

**World Dementia
Council** Leading the Global Action
Against Dementia

Global dialogue on care: Transcript

The dementia landscape
project

5 February 2021

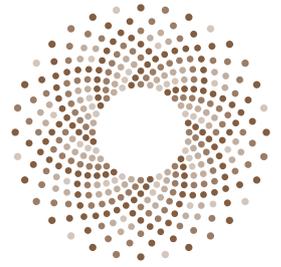


Organized in partnership with



**GLOBAL
BRAIN HEALTH
INSTITUTE**

Co-chairs



Professor Brian Lawlor

Brian Lawlor is a professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute. He is a geriatric psychiatrist with an interest in dementia, late-life depression, loneliness and brain health. Brian has worked for over 30 years on developing services and delivering care to people with dementia. His research interests range from early detection and prevention to evaluating new treatments for dementia. Brian also works with different stakeholders, agencies and research groups to understand the determinants of caregiver burden, particularly the impact of loneliness and behavioural and psychological symptoms, with the aim of developing strategies and policies to improve the wellbeing and quality of life of informal caregivers of people with dementia.

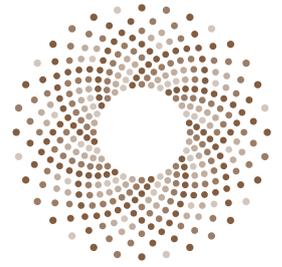


Paul Hogan

Paul Hogan is chairman of Home Instead® and a member of the World Dementia Council. He co-founded Home Instead with his wife Lori in 1994, and today the franchise network is the world's leading provider of home care services for seniors. It has more than 1,100 independently owned and operated offices that provide more than 60 million hours of care annually across 12 countries on four continents. In addition to his work with the World Dementia Council, Paul serves on the board of governors for the Global Health and Healthcare Partnership Community at the World Economic Forum and has previously served as the vice chair for the Global Agenda Council on Ageing.



Speakers



Professor Felicity Baker

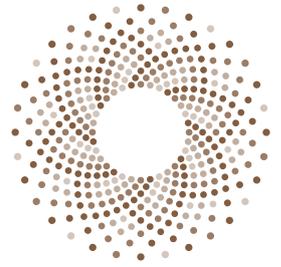
Professor Felicity Baker is Director of International Research Partnerships for the Creative Arts and Music Therapy Research Unit at The University of Melbourne. She has 28 years experience as a clinician and researcher and is currently principal investigator on two randomised controlled trials with people living with dementia. She has secured AUS\$13M in research funding and has published over 150 books and journal articles. Her world leading research is highly cited and has led to the Royal Commission into Aged Care (Australia) recommendation 18 that by 2024, all aged care providers must engage a music therapist or art therapist. Felicity has won numerous awards including being the second recipient of the World Federation of Music Therapy Research Award (2017) and an Australia Research Council Future Fellow (2010).



Professor Louise Robinson

Professor Dame Louise Robinson, is an academic GP and Professor of Primary Care and Ageing at Newcastle University. She was the first GP to be awarded a prestigious NIHR Professorship. Professor Robinson also holds the first UK Regius Professorship in Ageing. Louise leads a research programme focused on improving quality of life and quality of care for older people, especially those with dementia. She leads 1 of only 3 Alzheimer Society national Centres of Excellence on Dementia Care. Louise was primary care lead for the Prime Minister's Dementia Challenge and is a member of the National Dementia Care Guidelines development group.





Professor Mary Sano

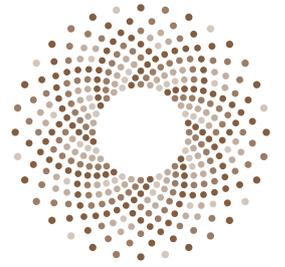
Dr Mary Sano is a professor of psychiatry and Director of the Alzheimer's Disease Research Center at Mount Sinai School of Medicine. She also serves as Director, Research and Development at the James J. Peters Veterans Administration Medical Center and is Immediate Past President (2019-2021) of the International Psychogeriatric Association. A neuropsychologist by training, Dr. Sano has been involved in designing and conducting clinical trials for the treatment and prevention of cognitive loss and dementia. She has also directed the development of neuropsychological assessment as outcomes for clinical trials in Spanish speakers in the United States and has developed methods for standardizing cognitive outcomes in clinical trial assessment in Europe and Asia. Her work also includes the development of methodologies to assess cognitive function in the elderly with special needs such as Down syndrome. Dr. Sano is a major contributor to both national and international organizations on the care and treatment of those with dementia.



Dr Samir Sinha

Dr. Samir Sinha is the Director of Geriatrics at Sinai Health System and the University Health Network in Toronto and an Associate Professor of Medicine at the University of Toronto and the Johns Hopkins University School of Medicine. He is also the Director of Health Policy Research at Ryerson University's National Institute on Ageing. A Rhodes Scholar, Samir is a highly regarded clinician and international expert in the care of older adults. He has consulted and advised governments and health care organizations around the world and is the Architect of the Government of Ontario's Seniors Strategy. In 2014, Maclean's proclaimed him to be one of Canada's 50 most influential people and its most compelling voice for the elderly.

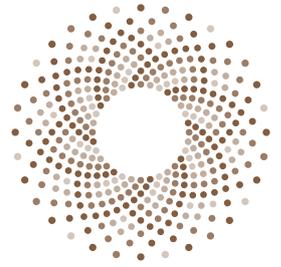




Lenny Shallcross

Lenny Shallcross is executive director at the World Dementia Council. Prior to that he was Head of Community Engagement leading programmes across the UK to establish Dementia Friendly Communities. This includes the Dementia Friends programme which is the biggest health social movement campaign delivered by 10,000 volunteers that have recruited 2 million individuals through a community, digital and corporate offer. Before working for Alzheimer's Society he worked in the UK government as a political adviser at DCMS and the DoH, as well as working in Parliament and for the Labour Party.





Global dialogue on care

Friday 5 February 2021

08:00 - 09:30 CST	Chicago
09:00 - 10:30 EST	New York
14:00 - 15:30 GMT	London
15:00 - 16:30 CET	Central Europe
19:30 - 21:00 IST	New Delhi
23:00 - 00:30 JST	Tokyo

Chat function

The chat function was available throughout the dialogue for participants to ask questions of presenters and to hold discussion amongst each other. It began just under 15 minutes into the event and is displayed below. It does not necessarily correspond with the adjacent transcript in this document.



Discussion transcript



Lenny Shallcross
Executive director, World Dementia Council

Welcome everyone. I am Lenny Shallcross the Executive Director of the World Dementia Council. I realise many of you have participated in council meetings before in one form or another. And I am used to welcoming you to a conference. So, it is slightly unusual to be welcoming you to my sitting room. But there you go.

But for those of you who have not attended one of our meetings before the World Dementia Council was established following the London Dementia Summit that was hosted in 2013 by the UK government as part of their G8 presidency. The Council was established after the meeting with the purpose of supporting and challenging the international community to deliver on the commitments they made at the summit.

The Council is chaired by Harry Johns who is President and CEO of Alzheimer's Association in the US. There are 24 members. Alongside them there are a number of government associate members and WHO and OECD are members.

As you know at the London summit the international community committed to make progress in research, care, awareness and risk reduction. This year the Council is producing a report evaluating the progress that has been made in those four themes. Where we have come from, where we are and what needs to happen.

As part of this work, we are holding a number of different workshops to inform this report. This being one of them. At each of these roundtables that we are holding we have brought together a range of global experts working in the field to share their insight



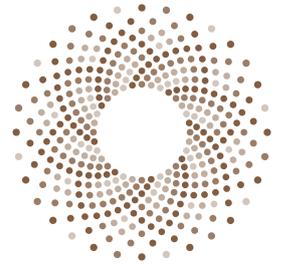
Paola Barbarino

Great presentation Louise, so interesting on the inequality point. And thank you for the numerous citations of our World Alzheimers Reports.



Sarah Lock

Appreciate you laying out the dementia care



and thinking. After this meeting we will circulate to you a transcript of the discussion including the transcript chat function (which I would encourage you to use as well). We will produce a number of essays from individuals reflecting the themes that we discussed today. And finally, we will share with you and invite your input on the care chapter of the report that we will be producing later this year.

I am very grateful to Louise, Mary, Samir and Felicity for agreeing to share their thinking at the top of the programme today and getting our conversation started. I would encourage you to participate in the meeting either live or using the chat function.

Before I introduce the co-chairs of today's meeting, a couple of brief points of housekeeping. After a year of these meetings, I am sure you are all used to muting and unmuting. As you can see on the screen itself, we are recording the meeting but that is for the purpose of producing a transcript. You will have received from Josh details of everyone participating in today's conversation.

So with that, I would like to introduce the co-chairs of the meeting. Paul Hogan is founder and chair of Home Instead and sits on the Council. Brian Lawlor is Professor of Old Age Psychiatry at Trinity College Dublin and Deputy Director of the Global Brain Health Institute. So, with my thanks to them both, I would like to hand over to Paul.



Paul Hogan
Chairman of Home Instead® and
member of the World Dementia Council

Thanks Lenny and greetings everyone. It's truly great to be here and part of this important discussion. I am really grateful for the leadership provided by my colleagues at the World Dementia Council for bringing us together around a very important issue.

Home Instead provides home care for older adults, wherever they call home. Whether a traditional home, care home or facility, hospice, or even living with a loved one. This includes relationship-based, person-centered care to help maintain health and independence, assist with the activities of daily living, aiding in combatting loneliness and social isolation for older adults when life can be very isolating, especially now.

Home Instead has more than 1,200 offices across 14 countries and today we will have more than 100,000 caregivers working with older adults in their homes and provide essential, life-sustaining and even life-saving care.

The reason dementia care is so close to my heart is because nearly two-thirds of our clients are living with Alzheimer's disease or other dementias. Families trust us to provide the best care for their loved ones, and we have an obligation to deliver it.

Alzheimer's Disease and other dementias as we all know is a rapidly growing crisis. None of us can truly quantify the human anguish of the 50 million individuals living with this disease, or the hundreds of millions of family members and loved ones who are caring with those who have the disease.

pathway addressing the spectrum of dementia care. Your slides will be very useful to share with others Louise. Thank you!



Lenny Shallcross

We will circulate all the slides after this meeting along with the transcript. [The World Alzheimer's Reports by ADI Louise mentioned are here.](#)



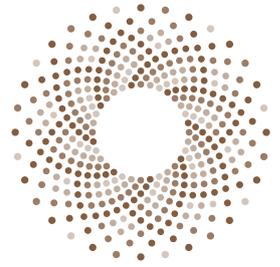
Dr Mariella Guerra

Need to evaluate in parallel what happens in LA countries for example.



Dr Stefania Illinca

Thank you, Prof. Robinson, for the great presentation. I'm wondering to what extent are the core components of dementia care you have listed specific to the UK context? Or rather, which of these components does your research suggest are highly relevant at European and global level?



Living with dementia presents challenges at any time, but now, we are in the midst of a global pandemic. Many people living with dementia and their care partners oftentimes lack the access to information about remaining safe during this crisis period.

Today, in many parts of the world, people living in care homes have frequently been banned from having visitors, and as a result, isolation and loneliness are at all-time high levels. Pressure on family caregivers and care partners continues to grow.

Covid-19 has highlighted the fact that we must revisit how we care for the elderly, especially individuals living with dementia.

To set the stage for today, I'd like to share a few numbers as they relate to care:

- In the United States, during 2015, an estimated 18 billion hours of informal care were provided for Alzheimer's and other dementias, valued at over \$221 billion.
- Globally, informal care hours in the same year, were estimated at 82 billion, 32 billion were provided in high income countries and interestingly the same number 32 billion were provided in upper middle-income countries.
- Dementia costs are estimated to be over \$1 trillion – this is approximately 1.1% of the global GDP.
- Total cost of care for the treatment of Alzheimer's or other dementias in 2020 was estimated to be \$305 billion in the U.S. alone.
- Across 15 EU member states, lost productivity due to Alzheimer's or other dementia resulted in an estimated €7.3 billion Euro loss.

Now, we all hope and pray for a cure, and I'm grateful for the incredible advances in science, innovation, technology, and healthcare. But today we are here to discuss care. Until there is a cure for Alzheimer's disease and other dementias, there is care.

As we discuss care, we must make sure people living with dementia are understood as individuals and treated with dignity and respect. We must also provide tools and resources to support the hidden heroes behind Alzheimer's – and they are family carers and care partners.

So, I am looking forward to today's presentations and discussion and thank all of you for your participation. At this time, I'd like to introduce Dr Brian Lawlor, you just heard he is Professor of Old Age Psychiatry at Trinity College Dublin and deputy executive director of the Global Brain Health Institute at Trinity. Dr Lawlor will lead our discussion today. Take it away Dr Lawlor.



Professor Brian Lawlor

Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

Thank you so much for that introduction to the care landscape. I want to add my welcome to everyone. I am just delighted you can join us today and give up your time to this very important issue.



Sarah Lock

Thank you Lenny. Mary, it's so interesting what you are saying. Your points make me think about suggesting the necessity for a triad of care, at least temporarily, a tech specialist to help with access for both the caregiver and the PLWD given the importance of tech access. Until we get to universal design that is easy to use for everyone dependability, usability, and lasting.



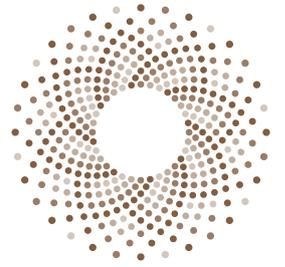
Professor Anthea Innes

Very interesting presentation Mary, did you work include the views of people living with dementia themselves in any way?



Emily Holzhausen

Mary, fascinating numbers, measurements and the human side of



When Paul and I have when shaping today's conversation we decided to invite four speakers to offer different perspectives on this topic to help shape the discussion. So, I am delighted we have:

- Professor Louise Robinson professor of primary care and ageing at Newcastle University
- Professor Mary Sano professor of psychiatry at Mount Sinai New York
- Dr Samir Sinha director of geriatrics at Sinai Health System and the University Health Network in Toronto
- And our fourth speaker is Professor Felicity Baker professor in music therapy at the University of Melbourne

So without further ado I would like to hand over to Lousie who is going to kick us off and give us an overview of the care landscape.



Professor Louise Robinson

Professor of primary care and ageing, Newcastle University

caring and tech. Reflections from the UK and supporting unpaid carers, this resonates very well. Completely agree about public policy looking more at digital/tech infrastructure as support when traditionally this might have been overlooked.



Professor Louise Robinson

Agree Mary re the need for a human touch to use of technology!



Jacqueline Hoogendam

In NL we have online guides for informal carers and care professionals to learn people, even with very advanced dementia, to use a tablet computer for video calling with relatives. It really works! With different reactions from the persons with dementia. Sometimes angry because the relatives don't take the

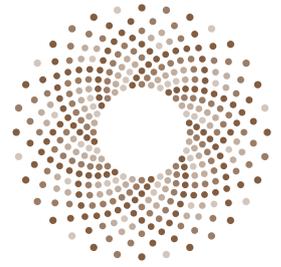
Alzheimer's Society
United Against Dementia
NHS
National Institute for Health Research

Newcastle University
Institute for Ageing

**21st century dementia care
....liberte, egalite, fraternite**

Louise Robinson
GP and Regius Professor of Ageing
a.l.robinson@newcastle.ac.uk

Thank you very much Brian. It is an absolute pleasure to be here.



trouble of visiting in real life. On the other side: a lady kissing the screen to say goodbye to her husband. The guide is available in English as well. This is the link to the document. This is the website, also explaining learning capacities in persons with dementia.



Barbara Osborne

That would be great to see Jacqueline. Our experience over the past 11 months has really highlighted the gaps in understanding and familiarity with technology to access support. Our team has had to talk through step by step in the majority of instances to help professional care givers to access online services.



Dr Iva Holmerova

Thank you very much for both wonderful presentation. My experience from

What a difference a decade (or two) makes...

2006: UK NICE dementia guidance

- Specialist led diagnosis and care

2011: World Alzheimer Report

- Role of primary care... 'under-used'

2011: PM's dementia challenges

- Role of primary care; prevention/risk reduction

2016: World Alzheimer Report

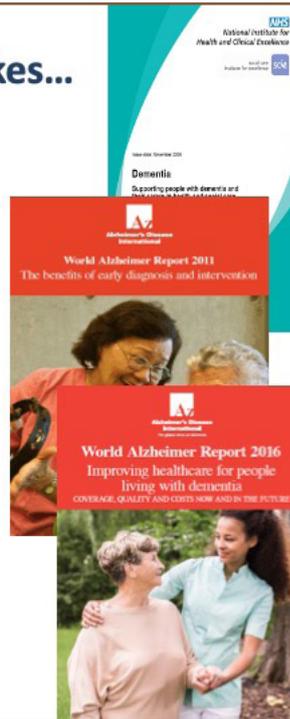
- Current care model unsustainable... task-shifted...

2018: UK NICE dementia guidance

- Expanded Primary care role

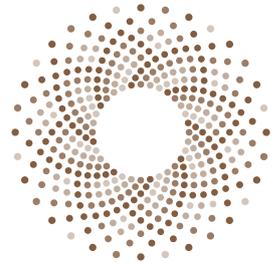
2022: World Alzheimer Report

- **Post diagnostic care**



As a dementia researcher, but also a family physician for many decades now, it has been really interesting for me to notice the subtle changes in policy that have happened over the last two decades in the UK. With the published very first guidelines in 2006 the emphasis was very much on a specialist care model led by old age psychiatrists neurologists and geriatricians. However, when these clinical guidelines were updated and published in 2018 there was a subtle shift and certainly the role of primary care was much enhanced, including the prescribing of dementia drugs.

In between, I have been keeping my eye on the World Alzheimer's Reports and noticed as far back as 2011 they commented that primary and community care was under used in the care of people with dementia once a diagnosis was confirmed. And they went further in 2016 by saying the current specialist led model of dementia care was unsustainable. Partly because of an increased demand from an ageing population and the numbers of people being diagnosed with dementia, but also from a cost effectiveness perspective and obviously delivering care in a primary care was usually much more efficient. It will be interesting to see what the 2022 report from ADI says because that is also focused on post diagnosis care.



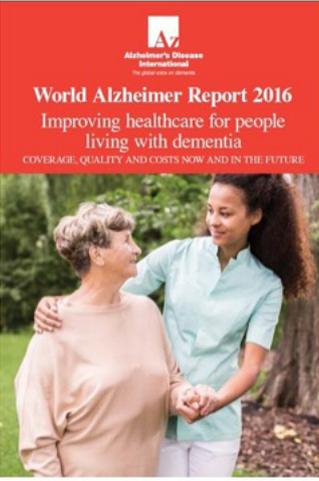
 **Centre of Excellence: Newcastle University** 

PriDem programme (2018-22)
*Primary care-led efficient, integrated and sustainable post diagnostic **Dementia** care*

1. *Global evidence + national mapping*
2. *Current practice: user/provider views*
3. *'Good practice' model development*
4. *Testing in 'real world' settings*
5. *Economic evaluation*
6. *Impact on policy and practice*

'Dementia Care Community' (PPPI)

Team: UCL, Manchester & Brighton Universities, London
School of Economics, Dementia Care



ouf Centre of Gerontology in Prague: we employed part-time two young students who during the central visit ban and lockdown connect our patients with their relatives - so that they can follow their progress in rehabilitation etc. Very nice feedback from both sides.

But I am here today to talk about some of the research that we are doing here in the UK that is funded by the Alzheimer's Society as one of their three centres of excellence in dementia care research.

I lead the PriDem programme here at Newcastle University which was very much generated from the World Alzheimer's Report that suggested primary care needed to be much more involved, and was a more efficient and feasible way of delivering, care to increasing numbers of people with dementia.

This is a four-year programme and it started by looking at the current evidence that we could find out there both nationally and globally. By trying to map what was happening here in the UK in terms of current practice and service delivery. Then doing a very detailed bit of qualitative research by trying to explore that service provision in detail and talking to all key stakeholders: people with dementia, carers and service providers. From this data we hope to develop a good practice model, or models, which we are then going to test out and evaluate and certainly not just look at effectiveness but also the costs with our colleagues at the London School of Economics.

The interesting aspect of this programme is that I am used to having public and patients involved in my research or PPI as we call it here in the UK. But this is the first time I have brought together professionals, together with patients and the public and we now have a dementia care community of over 80 people, a third people with dementia, a third family carers and a third service providers who have helped inform and deliver and also disseminate this programme of work.



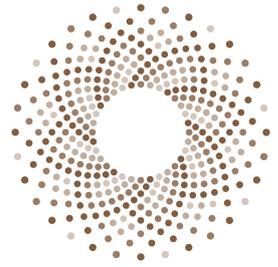
Paola Barbarino

Is anyone attending has more great examples like Jaqueline's of telemedicine/health being used to great effects during Covid-19? If so please send them to me at p.barbarino@alzint.org



Sarah Lock

Samir, there are some state based Medicaid programs in the US that allow for paying family members (but not spouses) but there are always the idea that it might be rife with fraud. Since the institution of the



benefit in Canada since 2017 have you seen any issues? In the evaluations we have seen we have found very little fraud but enormous savings instead.



Professor Morris Freedman

Yes, at Baycrest, we have developed a virtual inpatient unit without walls to assess patients with dementia and aggression and agitation in long-term care, acute care and the community. We have reduced the need for admission to acute care and specialized behavioral units by almost 80%. We are writing this up for publication.



Professor Mathew Varghese

During Covid I think what really helped was simple voice calls on the cell phone on an SOS basis when CG faced some difficulties.

Research

Rachael Frost, Kate Walters, Su Aw, Greta Brunskill, Jane Wilcock, Louise Robinson, Martin Knapp, Karen Harrison Dening, Louise Allan, Jill Manthorpe and Greta Rait; on behalf of the PriDem Study project team

Effectiveness of different post-diagnostic dementia care models delivered by primary care:

a systematic review

ged version published in
 Br J Gen Pract 2020; DOI:
<https://doi.org/10.3399/bjgp20X710165>

Results

- **23 papers:** 4 countries (USA, Germany, Netherlands, Singapore)
- **10 studies (9 interventions):** 5 RCTs and 4 controlled studies
- **4 types of Primary Care (PC) models**
 - PC provider led; PCP-led with specialist care; PCP case management; Integrated PC memory clinics

➔ **PCP nurse case management model most promising**
 impact on BPSD, carer burden & distress, care costs
(Specialist nurse: care-coordinator/named lead professional)

We are now over half-way though. We finished our evidence synthesis and that included three systematic reviews. The first was a traditional systematic review looking at the clinical and cost effectiveness of different models of post diagnostic dementia care delivered by primary care. We found 10 studies, none from the UK, which we included in our review and 4 different types of primary care models. The evidence both in terms of clinical and cost effectiveness suggests a specialist nurse case management approach was the most promising primary care model for delivering post diagnostic care.

Evidence synthesis

Aging & Mental Health

1294-1310 | doi:10.1080/13607862.2020.1820000 | <https://www.tandfonline.com/doi/full/10.1080/13607862.2020.1820000>

Implementing post diagnostic dementia care in primary care: a mixed-methods systematic review

Rachael Frost, Greta Rait, Su Aw, Greta Brunskill, Jane Wilcock, Louise Robinson, Martin Knapp, Nicole Hogan, Karen Harrison Dening, Louise Allan, Jill Manthorpe, Kate Walters & on behalf of the PriDem team

Received: 27 February 2020 | Accepted: 1 June 2020 | Accepted for publication: 24 June 2020

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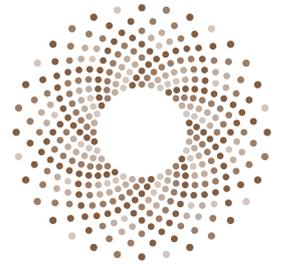
REVIEW ARTICLE

What works in managing complex conditions in older people in primary and community care? A state-of-the-art review

Rachael Frost PhD¹ | Greta Rait MD¹ | Alison Wheatley PhD² | Jane Wilcock MSc¹ | Louise Robinson MD³ | Karen Harrison Dening PhD³ | Louise Allan PhD⁴ | Sube Banerjee MD⁵ | Jill Manthorpe MA⁶ | Kate Walters PhD⁷ on behalf of the PriDem Study project team

- **Dementia expertise in PC**
- **Collaboration + specialist care**
- **Service provider engagement + leadership**
- **Good links + social care/community services**

- **Explicit theoretical underpinning**
- **Patient self management**
- **SMART intervention outcomes**
- **Structured, formal collaboration e.g. shared care pathway**



We then did a review looking for factors that would influence positively the delivery of post diagnostic dementia care in primary and community settings. This was a very large review, a mixed method one, key and we found factors such as having dementia expertise based in primary care, formal collaboration with specialist care and good links with other service care providers such as social care and third sector, together with leadership and engagement from primary care staff were key positive factors.

We also looked at other long-term conditions such as diabetes and Parkinson's which have been more traditionally in the UK led in primary care and found that having structured formal agreements such as formal shared care pathway between primary and secondary care was another key factor.



Professor Louise Robinson

Yes and continuity ie contact from a known person.



Sarah Lock

Love that as a provider you can prescribe respite for the caregiver.



Adelina Comas-Herrera

Many European countries are also paying family carers, in very different ways, interesting implications for people who combined family care and paid work, [this paper by LSE colleagues](#) gives a great overview of options.



Dr Mariella Guerra

The same in LA countries... paying family carers.



Grace Whiting

Lenny, thank you for inviting me to this meeting



Qualitative studies

Open access Original research

Key stakeholder views
Commissioners, providers, managers (n=61)

Good practice: 6 case studies

- Specialist dementia nurse in general practice
- GPs + extended role (GPWERS) across a CCG
- Third sector community memory support workers
- Secondary care enhanced memory assessment service
- Secondary care step up/down models + GP practices (x2)

BMJ Open Task-shifted approaches to postdiagnostic dementia support: a qualitative study exploring professional views and experiences

Alison Wheatley ¹, Clare Bamford ¹, Greta Brunskill ¹, Karen Harrison Denning ^{2,3}, Louise Allan ⁴, Grazi Rait ¹, Louise Robinson ¹, The PriDem Study project team

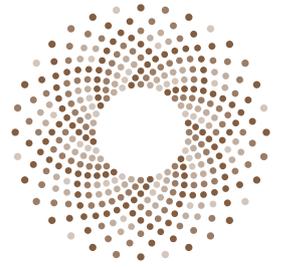
‘FRAGMENTATION & FRAGILITY’

‘INEQUALITY & INSTABILITY’

- Huge variability in provision –especially NICE recommendations
- Funding major challenge to sustainability
- Lack of integration: duplication of effort and resource
- Primary care concerns: lack of capacity, skills and willingness
- Practical issues: lack of shared care pathways; data sharing; specialist access

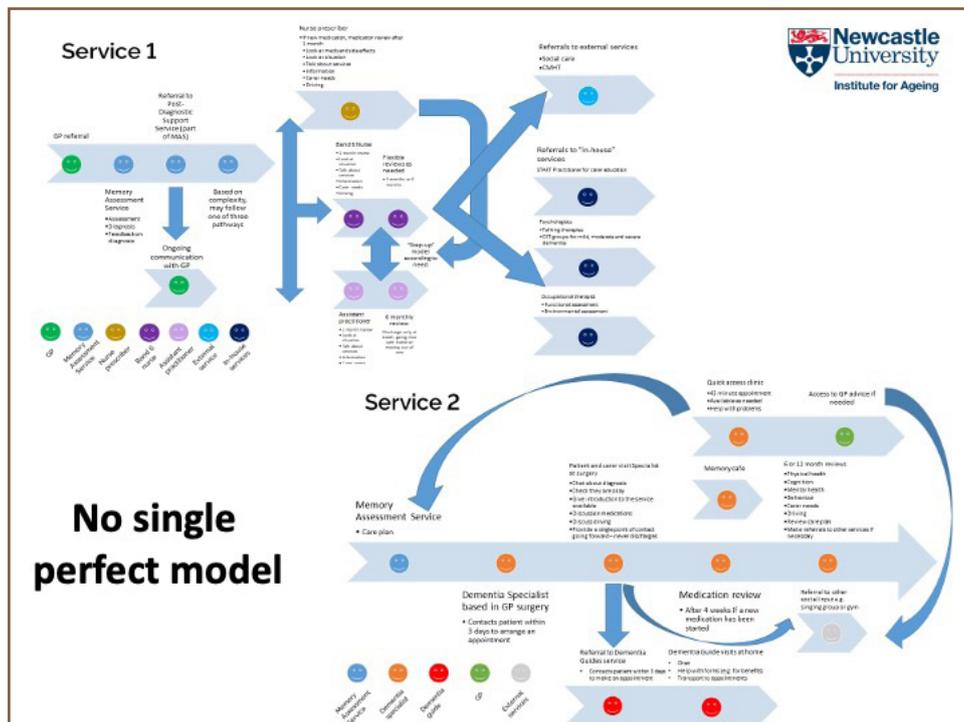
While these reviews were going on, we undertook our qualitative work. From our national mapping survey we were able to identify over 60 people to take part in individual interviews. These were service commissioners, service providers and service managers of post diagnostic care. We talked in detail to them of what the current care was, what difficulties they have and what facilitators there were to delivering care and where importantly the money came from for this service provision.

From this study we were also keen to identify examples of good practice. We identified six case studies. These weren't all primary care led some were. But some also had heavy involvement of primary care in terms of being well linked to secondary care memory clinics involving shared care pathways and step-up step-down models. We then went to these sites and did observations and spoke to people with dementia, their carers and service providers to get even more data on what made these models work and why they were considered to be good practice.



At the end of this what we found was very surprising even by our standards as expert researchers in this area. There was much greater inequality and instability of post diagnostic care than even we thought and geographical inequalities were huge even at these short distances. Funding for health care was actually very short and a major challenge to providing sustainable models of post diagnostic care. There was often very little integration between primary and secondary care and also social care. And often duplication of effort especially during the first couple of years. And primary care were concerned they didn't have the time or skills to deliver what they considered was complex care. There were very few shared care pathways available and even long standard evidence-based interventions like cognitive stimulation therapy which had been recommended in the first NICE guidelines back in 2006 was not routinely available.

on behalf of the National Alliance for Caregiving in the US. It's particularly interesting to hear how these care programs have changed over the years under different governments.

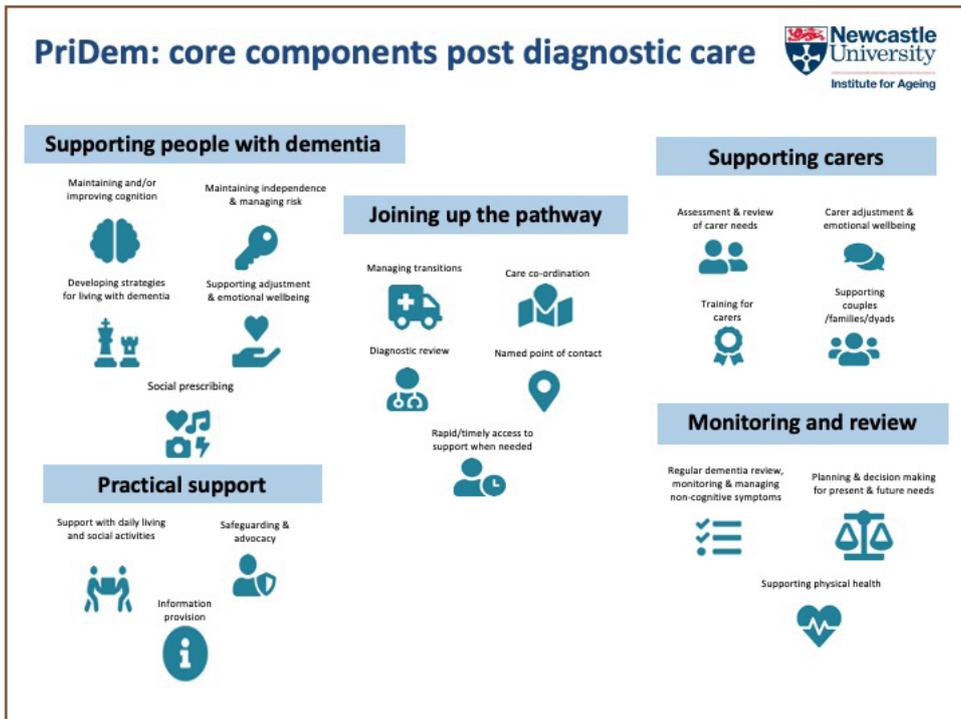
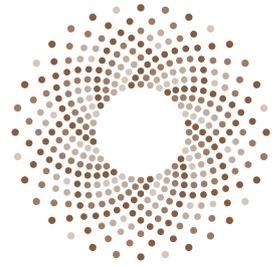


Paola Barbarino
 Yes good point Adelina! and the Italian government's most recent dementia law provides for financial support for family carers (first time the Italian government funds a portion of its national dementia plan by the way...)



Emily Holzhausen
 We have a few limited areas in England with clinicians able to give a "breaks prescription" as Samir suggested, but only at primary care level. It tends to be a "one off" and up to £500 value, but doctors have fair discretion within

So what we found when we were working and doing our close in depth work in the six sites was there was no single perfect model in the services we observed in England. They all worked in different ways and provided different combinations of services and evidence-based interventions as showed by these two examples of service mapping from two of the six examples.



What we did find was if we looked across all of our data there was some core components of care which did include evidence-based intervention such as delivering behavioural therapy and delivering care coordination that were core to providing good quality post diagnostic dementia care. And we have called these the PriDem components of post diagnostic care.

that to prescribe. It can provide a lifeline. Delighted to hear of the practice in Canada and we wish it were more widespread!



Professor Mathew Varghese

Agree with Mary that the online program needs to be easily accessible on simpler devices like a phone or a tablet. Many times the CG is an elder spouse who may find complicated programs and devices difficult.



Sarah Lock

We are thinking of creating a pilot, and if you don't mind I will suggest this be included and tested for economic and clinical benefit!



Helen Rochford-Brennan

In Ireland we have a Carers grant and one a year substantial respite grant, nice to see Canada has introduced. Thanks

PriDem intervention

WHO: Dementia clinical expert - nurse specialist
supported by a local multi-disciplinary team of existing generalist/specialist staff (e.g. GP, nurse, pharmacist, dementia advisor, social prescriber), linked into social care and third sector resources

WHERE: Primary care network (40,000 patients)

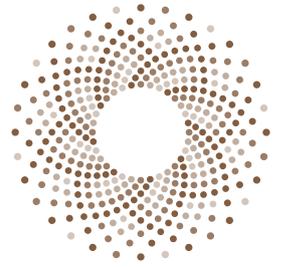
WHEN: Post diagnosis to end of life

WHAT: Focus on 3 key areas:

- **Building capacity:** supporting non-specialists to deliver dementia care and support
- **Improving systems:** formalized, integrated delivery of evidence based support
- **Personalised care and support;** meet the complex needs of with people living with dementia and their informal carers

HOW: Dementia care pathway (NICE + PriDem components of care)

- Baseline mapping (focus on transitions: service user and provider)
- Clarification of roles/responsibilities; mutually agreed final LOCAL DCP



So what we have spent the last six months doing is bringing together all the data from our evidence reviews and our qualitative data to develop an intervention that we are going to test out in primary care. It is clear that we need to have clinical expertise based in the community and we are going to test that with a nurse specialist as shown by our systematic review. The key roles of that specialist will be to bring together key individuals involved including specialists and to develop a, if you like, dementia care ecosystem within the community to deliver a more integrated service provision from post diagnosis right the way through to end of life. It will be very much around setting a formal shared care pathway where everyone hopefully knows what they are doing at what time and when with a mutually agreed delivery of care and roles and responsibilities.

everyone for presentations... not sure I am hearing much about "our voice" in care plans.

The following list summarises the main issues at each stage of the pathway:

Diagnosing well:

- People are being misdiagnosed, particularly younger people, or opportunities to identify dementia early are being missed. Referral processes can be confusing, with people feeling daunted about "what comes next"
- Variation between memory services and limited performance data can make the initiation of service improvement projects challenging.
- Delivery of a diagnosis, including a subtype and tailored information, is variable, and too often focuses on what people can no longer do, rather than what they can do.

Supporting well:

- Information provided at the point of diagnosis is not being delivered in the right way, if at all
- People are struggling to access a care coordinator. This could significantly help people navigate the complexity of the health and social care system to get the right care and support.
- Care planning, including advance care planning, if undertaken, can be insufficient and dementia-specific needs are not considered. This is made worse by a lack of integration of care and support plans.
- The provision of post-diagnostic support interventions – those that exist from national guidance and based on clinical evidence – can be variable and inappropriate.

Living well

- People receive limited access to coordinated, proactive and ongoing care and support. Follow-up care is not the same for everyone living with dementia, and many people are left to manage their condition themselves.
- Many people receive most of their support from their primary informal carer, but carers are struggling to access support services for their own wellbeing.
- Hospital and care homes need to identify and accommodate dementia specific needs. They must ensure access to the right services at the right time.

Dying well:

- Dementia is a terminal condition, meaning those with the condition will live with it until death. Despite this, people often struggle to access palliative care, including end of life care.
- Advance decisions are sometimes ignored, meaning the interests of people and their wishes at end of life are not being fulfilled.

From diagnosis to end of life:
The lived experiences of dementia care and support




 **Dr Mariella Guerra**

It would be great to include LMIC in that.

 **Professor Martin Knapp**

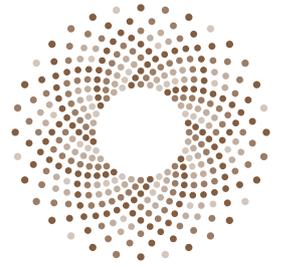
I'm biased (as a co-I) but I would recommend looking at the START programme for supporting family carers of people living with dementia. It is easy to deliver, improves carer mental health and quality of life, and it is cost-effective, even 6 years after delivery.

 **Sarah Lock**

Hooray for our Australian friends who are able to join us at these dreadful hours for you! Thank you!

We are very fortunate in being funded by the Alzheimer's Society, but they are also playing a huge part in impact on policy and practice and disseminating some of our findings. And some of our early findings contributed to this excellent report looking at the dementia care pathway published a couple of months ago.

So actually, I think we all agree certainly from the PriDem team that it is time for a bit of a revolution of dementia care in England. Every person with a diagnosis of dementia should be able to get evidence base therapies that are currently recommended by our national NICE committee. No matter where they live, they should get a standard of care that should be core nationally. It is time for us as a community both primary, specialist and social care to come together to deliver a more joined up approach to post diagnosis care.



Professor Brian Lawlor

Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

Great thank you very much Louise for that. I just want to hand over to Mary Sano who is going to talk about supporting caregivers through technology.



Professor Mary Sano

Professor of psychiatry and director, Alzheimer's Disease Research Center, Mount Sinai School of Medicine



Katie Brandt

Samir, thank you for that presentation. The financial implications of dementia and subsequent financial benefits of helping carers is so impactful. The model that you described with small group opportunities for education and support is something we should all strive to “rob and duplicate”



Professor Shekhar Saxena

Just to flag, WHO has iSupport: a programme for carers of people with dementia, in [text manual](#) and [an online portal](#). Perhaps also time to revise it in light of Covid-19.



Barbara Osborne

Totally agree, music helps you to see the person behind the dementia.

Technologies to Support Caregiving: Challenges and Opportunities

Mary Sano, PhD

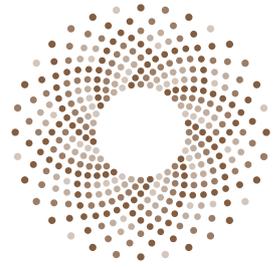
Alzheimer Disease Research Center

Mount Sinai School of Medicine

James J Peters Veterans Affairs Hospital



Thank you. I appreciate the opportunity to join this group. I have to say what I am sharing with you is experiences of translating our use of technology in traditional research settings to collect important clinical data to the community of carers who often reflect many of the same concerns that researchers do.



Technology and Caregiver

- This population of caregivers is estimated to be 45 million, caring for 117 million people.
- 71% report being interested in using technology for caregiving
- 59% report having some technologies
- Only 7% are currently using it for caregiving
- Multiple reasons for the gap
- Age, low education and income increase the gap

Caregivers & Technology: What They Want and Need (2016)

In my first slide I also want to make a comment that the concept of technology is broad, and I have tried here to focus on how we match up technology with caregivers desires and skills. And I took this first report from 2016 and much of this has not changed in a recent update of it. Reporting that more than 45 million people are caring for over 100 million patients.

What was fascinating was everyone talks about being interested in using technology for care. And you can bring in many more knowledge people who can tell you about the very highest degree of information that we can gather from these populations. But my intention is to talk about things that are functional and meaningful for caregivers. About 59% of these same caregivers say they do use some technologies they use phones or tablets. So, the common communication is that everyone has these technologies and so we should be using them. But in fact, we know that many people have technologies that they are not comfortable using them to their full extent. And only 7% of this survey of caregivers were currently using their technologies in caregiving whether it be a smartphone or tablet etc.

And there are multiple reasons for that gap. In particular the demographics of the caregiver: so age, lower education or income actually increases the gap between what people would like to do and what they are actually doing. So those things are crossing every survey that we see especially as carers, both formal caregiving and family caregiving are often older individuals the gap is made larger.



**Professor
Louise
Robinson**

iSupport currently be tested in a range of places worldwide.



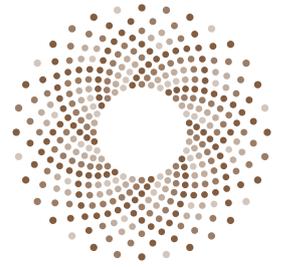
**Dr Samir
Sinha**

Sarah, to answer your question about the Caregiver Benefits in Canada - I have not heard of issues with Fraud. The bigger issue is that most of Canada's 8.1m caregivers don't know about these financial benefits.



**Grace
Whiting**

One of the interesting things about music therapy is that it gives carers and the person they're caring for something to do that is activity, social-focused, rather than making everything they do together really focused in on the care needs. Do the carers get to pick the music? And can they pick music that has meaning to the person who needs care?



What caregivers want from technology

- **Reliable connectivity**
 - Challenged by frequent “upgrades”
- **Easy to learn/easy to use**
 - Dependable way to problem solve and get help
- **Security, protection from scams and annoyance**
 - Clear rules about trusted sources for information
- **Health management**
 - Telehealth
 - Medication ordering, delivery, adherence
- **Socialization**
 - Access to activities
 - Human engagement
 - Support
- **Household management**
 - Scheduling
 - Shopping
 - Access to repairs and maintenance, services

So, what do caregivers want from technology. On the left side of the slide, you can see some of the things we all say we can deliver. But for anyone who finds that their voice will fade out during this you know it is not so dependable or reliable. So reliable connectivity is a real demand or a real source of frustration if it does not exist. And it is challenged by frequent upgrades of much of the equipment that we use, both of the software and hardware. And these changes are really a challenge as we age and are more removed from the typical high-tech user of technology.

Another request is to ensure that it is easy to learn and easy to use. Users are looking for Dependable ways to problem solve and to get help when needed. And as you know the transition of how one gets help has really changed with "technology" – there is no such thing as a manual – you look for online help. Again not necessarily readily available or familiar to most of our caregivers.

And finally, security and protection from both scam and annoyance is a real demand particularly in this age group. The fear that activating technology will give away critical information, will harm an individual or someone they are taking care of, is a real concern and what caregivers speak to when asked about technology.

On the right side of the slide you see a list of easy-to-understand expectations of technology including tele-health, medication ordering and delivery and adherence. Something we can simply expect from technology. In addition, and really critical both to the care of the patient and the support of the caregiver, is the socialization that technology can provide. Thinking of technology in terms of your ability to communicate with people beyond your geography, whether they be health care providers or friends or other support. The technology can provide access to support, to activities and human engagement, and other social and mental health support. And finally, household management, which can be requested or engaged through technology, but the ease



Jim Pearson

About Digital and Me (ADAM) is a digital assessment co-designed by people with dementia and Alzheimer Scotland (Digital team) supported by the Scottish Government Technology Enabled Care Programme. Its designed to find digital and other tech (including low tech) personalised solutions It's online at present given the current pandemic but would normally also offer home visits to carry out a personalised assessment. [More information here.](#)



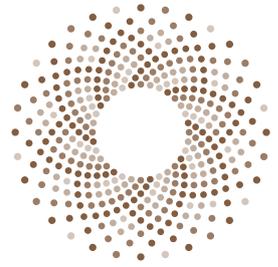
Professor Louise Robinson

And it's very person centred.



Barbara Osborne

It is really important to be able to be able to choose music that has meaning to the individual.



of use is really critical for the caregiver who must always think first not about the technology or tool but about the person they are caring for.

Interest in Telehealth Among Adults Age 50-80

- Only 4% had a telehealth visit
- Perception: Telehealth vs. In-person

- Convenience: same or better 65% better(T)
- Clinically:
 - Feeling cared for (56%) IP
 - Communicating (55%) IP
 - Time with HCP (53%) IP
 - Quality of care (58%) IP

When Telehealth holds advantage¹



Latino & African American Concerns²

- Privacy and Confidentiality

¹ Survey: N=2,256; resembles US population; 50-80 yo; May 2019

² George et al 2012

 **Professor Claudia Cooper**

Paola, we are currently trialling the NIDUS manualised and modular intervention (linked to GAS), cant say if works or not yet as trial doesn't report until 2023, but its all been on video-call (83%) or phone (17%) (as the trial started April 2020) and working well thus far in terms of low drop-out. The feasibility was pre-Covid and face-to-face [but you can find it here](#).

 **Professor Mathew Varghese**

Yes Shekhar you know we completed the first trial of iSupport in India. Outcome paper just being published in IJGP.

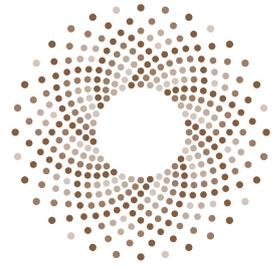
 **Helen Rochford-Brennan**

Thanks Jim.

This is a survey that was published some time ago now, but in a recent update we have looked at. Some of the challenges for example are the use of tele health, a simple technology that can reduce the burden of travel for patients and caregivers.

The phenomenon observed is that in this group of individuals between 50 and 80 only 4% had had telehealth visits. Even today in our Covid-19 rampant culture the number of telehealth visits among this age group is relatively low and it is actually almost always delivered if someone outside the immediate caring can come in and help arrange the visit.

However, when it is done there is really a perception of value. The convenience is appreciated, the face-to-face communication, the time with the health provider and the quality of care. Many have noted the telehealth visit gets better rating than the in person visit. Not necessarily because of the visit but the environment. Keeping someone safe in their home environment. And I think what is really interesting here in the US our under-represented groups are really worried about privacy and confidentiality using these technologies. And that is perhaps to be expected.



Telehealth in Multiethnic Caregiver Support Group: Transition from Telephone to Video in the Age of COVID-19



Meria Loizos, PhD¹, Shehan Chin, LMSW¹, Mari Umpleire, PhD, LCSW¹, Mary Sano, PhD^{1,2}
1. Icahn School of Medicine at Mount Sinai, New York, NY, USA; 2. James J. Peters VA Medical Center, Bronx, NY, USA

- Success of peer to peer training to transition

Satisfaction Responses

- What was the most helpful part about transitioning the support group from telephone to video?

“Connecting with the group, seeing the other participants”

“Seeing their eyes”

“The experience has become more personal now that I can see everyone. I wasn’t sure if I would like it but during this period of being locked away from human contact it was a good change”

“Connecting with people over video creates a greater capacity for understanding and compassion with and for each other

So, I am reporting here on something presented at the International Psychogeriatric Association meeting this past fall where we describe the use of telehealth to engage a multi-ethnic caregiver support group.

This peer-to-peer group had been meeting by telephone and in the age of Covid-19 where they had reduced rather dramatically the ability to communicate with others, they explored the possibility of transitions to video conferences. So, this peer-to-peer training to do the transitioning was particularly successful. And I found it really enlightening to see what the things were, the small things, that technology can provide that was the highlight of the transition. Individuals felt that connecting with the group in a visual way being able to see people, their faces and eyes, really enhanced what they got out of the support. These really small things, which we all recognise, make a real difference in the caregiving setting.

Considerations

Addressing Barriers to Adoption

- Caregivers perceive cost as the biggest barrier
 - Device and service is low; advocate for public support
- Caregivers experience lack of confidence in learning technologies
 - Consider multi-generational and peer support for teaching technologies
- Balance of innovation with familiarity
 - “New look and feel” not appreciated by caregivers who want dependable functioning
- Encourage persistent interfaces, and universal or interoperable platforms.



Grace Whiting

Barbara, that’s my thinking too. My mother might like the Beatles, my dad might like Chicago. But if I play Donny Osmond, that may make matters worse! (No offense to the Osmonds.)



Professor Louise Robinson

So a trial of the Beatles versus the Osmonds?



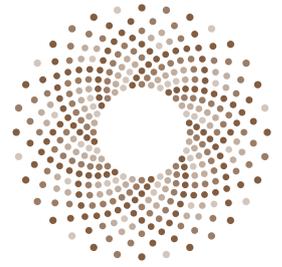
Professor Shekhar Saxena

Mathew, thanks, will be good to get the paper circulated to all attendees through WDC.



Professor Noemi Medina

Admirable speakers today many thanks. Associations of Alzheimer Iberoamérica AIB, 21 and more than 300 groups. despite the situation Covid from the beginning in same month march agilely reacted and



So, I want us to think rather broadly about inadvertent barriers that go into place when we think about these technologies. Caregivers perceive the cost as one of the biggest barriers and yet simple effective devices and services can be inexpensive. In fact, in my local geography the city made available free internet services which was not thought of as being so important to the support of individuals but it is an inexpensive barrier that can be overcome rapidly.

Caregivers experience lack of confidence in learning technology. And I think we need to think more broadly about how we can engage caregivers in the opportunity to ask questions and learn. Multi generation learning and peer support is a way to develop in teaching these technologies.

Balancing innovation with familiarity; there is such great value put on the newest and best and the new look and feel. But in fact, caregivers really want dependability and functional technologies that are ready-to-use and don't need much re-training and the seamlessness of that transition from one technology to another is a really important thing in making sure people make the most of it.

And finally, there is potential value in encouraging with guidelines or regulation persistent of an interface or the universality of interoperability of platforms. The fact that a new product identifies itself as unique and individual is not necessarily of value in a caregiving situation where one wants to take on these tools.

These are not conclusions but rather things for us to consider and discuss as we think about how communities address these barriers.

carried out coping actions starting with Support Groups for relatives, rescue Stimulation activities to reach people at home, organized talks and conferences, Alzheimer's Café, using music, updated networks and gradually appreciated the positive effect of on line experiences, the use of technology and good practice (ZOOO, ect=as postlal).



Professor Brian Lawlor

Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

Thank you very much Mary. Now I would like to call on Samir who is going to give reflections on supporting caregivers in his home country of Canada.



Lenny Shallcross

Mathew I will follow up with you if I may to get the paper and circulate it.



Dr Samir Sinha

Director, Geriatrics at Sinai Health System and the University Health Network in Toronto

Thank you very much. It is a real honour to be here and share with my colleagues. It is really great to follow on from the other presenters because it shows to some extent how Canada is a bit behind the game in certain respects but also how it is ahead. So hopefully this will be a useful sharing today.



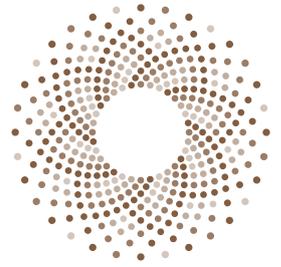
Barbara Osborne

More that it is not an assumption that certain age groups will all like specific music and that's a great example Grace.



Grace Whiting

Louise, exactly! Would be fascinating to know how the



Caring for Canadian Caregivers



Dr. Samir K. Sinha MD, DPhil, FRCPC, AGSF
Director of Geriatrics, Sinai Health and the University Health Network
Director of Health Policy Research, National Institute on Ageing
Member, Ministerial Advisory Board of Dementia
Associate Professor of Medicine, University of Toronto and
Assistant Professor of Medicine, Johns Hopkins School of Medicine

World Dementia Council Care Workshop
5 February, 2021

@DrSamirSinha

type of music and connection to the person works. Not to be too gloom and doom, but in the US at least, there's been military weaponization of certain music as torture. So as silly as it sounds, the music itself matters! For reference.



Sarah Lock

GCBH recently did a report on music and brain health, and its about personal preferences.



Lenny Shallcross

If you raising your hand keep it up so we can spot it. I saw Mariella Guerra and also Mike Hodin.



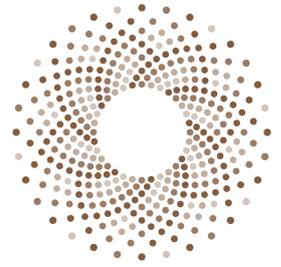
Jacqueline Hoogendam

Can I tell something on using abilities in persons with dementia for more quality of life?

The Canadian Context

- In June 2017 - Bill C-233 The *National Strategy for Alzheimer's Disease and Other Dementias Act* (the Act) requires the Development of a National Seniors Strategy.
- In June 2019, Canada launched its **National Dementia Strategy** and 50M over 5 years to support it.
- Increased recognition and support for Caregivers has been evolving over the last 5 years:
 - 2017 **Canada Caregiver Credit** that provides up to \$6,883 (adjusted annually for inflation) of tax relief a year to family members supporting the care of a relative
 - 2017 **Family Caregiver Benefit** was introduced to give unpaid family caregivers access to up to 15 weeks of Employment Insurance (EI) benefits when taking time off to care for a relative with an acute illness
 - 2017 **Compassionate Care Benefit** was improved to support unpaid family caregivers, going from 6 weeks to up to 26 weeks of EI benefits when taking time off to care for a relative with end-of-life care.

So just to give you some context for Canada overall. Canada was late to the game, if you will, to develop a dementia strategy. We were last, or second last, country to do this. It was not something the government willingly started, but it was legislation proposed by a member of parliament that compelled the government to develop a dementia strategy. So that was a two-year process that was launched in June 2019 and Dr Reichman, who is on the call here, is the co-chair of our ministerial advisory board on dementia which I am a member with him on.



So that was Canada's first foray two years ago in terms of having a national dementia strategy with \$50million over five years specifically dedicated at that time to support it. And that has been important for a national agenda. But like some other countries while we have a federal strategy much of the care and support that occurs that would support someone with dementia and their care partners is determined at a provincial and territorial level. So, in Canada we have 13 provincial and territorial health care and, therefore, dementia care systems.

The federal government is trying to provide an overall supportive role as well. When we think about the role of caregivers and care, one of the things the federal government has been particularly helpful in doing is recognising the value and role of caregivers and figuring out ways through national policies and initiatives where it can better support caregivers. And this is something that is quite unique and something I and others across Canada have campaigned for was better financial and other support for caregivers.

2017 was a milestone year because we recognised that the average Canadian caregiver was spending about \$3,500 providing support to a loved one. So, the Canada Caregiver Credit is a tax credit, that was created in 2017, that a care partner can apply for. And you can share this if you will, so for example two daughters providing care can share it share this with others if you will. So for example... there are some limitations on this. You have to be a family member – you can't be friends or neighbours who might be playing this important role. And you have to have an income under which you have to claim the credit. So if you are not working and you are not drawing an income you would not be eligible. So this is great start, and my colleagues in the US say it is amazing you have a caregiver credit, but it still creates some access issues to some in particular.

We also created and upgraded on previous benefit and created a new one. In Canada we had something called the Compassionate Care benefit and it is one where you could use your unemployment benefit to be supported financially if you had to take time off work to support someone who is at the end of life. It originally used to be for about six weeks of support, but it was extended in 2017 to 26 weeks to recognise that people often need a lot longer than a six-week period to provide support with some greater financial security and support from the government.

In 2017 the Family Caregiver Benefit was also created because there was a lot of criticism that the only way you could get some paid time off to provided support to a loved one was only if they were dying. So, a new family caregiver benefit was created recognizing that you might have an older relative for example or a family member who might have an acute illness, like a hip fracture for example, and it would give you 15 weeks of employment insurance support. Again, the goal of this new benefit is to recognize the benefit family care givers provide.

Because right now in Canada it is believed to be about \$24-30 billion that family caregivers save the healthcare system by providing unpaid care and support. So, these are just some of the changes that were made. Including in fact legislating across all the provinces and territories protected job leave for family carers, so that if you did have to do one of these things, your job was protected. It varies, every province uses a different number but on average for about 12 weeks for protected job leave.



Grace Whiting

Sarah, what a fabulous report. Thank you for sharing this!



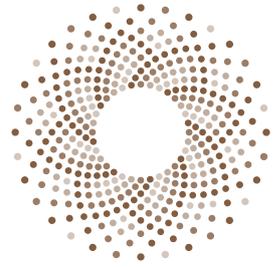
Professor Anthea Innes

The presentations all gave excellent examples, but I do think that to get to where we might aspire we need much more involvement, real and meaningful, from people living with dementia themselves. We have more and more examples of models that work in terms of activism and involvement in decision making but these are pretty localised and still need to be more widely used.



Lenny Shallcross

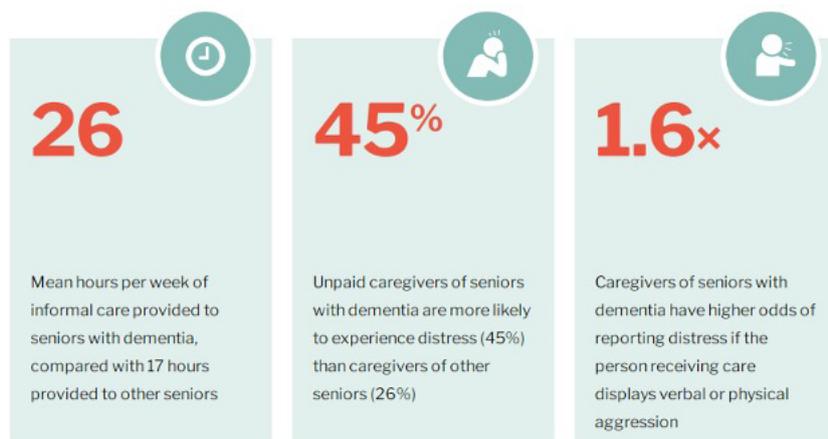
Anthea, isn't this one of the biggest challenges scaling up?



Part of all of these things, as I was involved with others in the advocacy around this, was the appeal to the minister of finance. Because we want to recognise that 1 in 3 working Canadians is also balancing unpaid care. And if we cannot support working Canadians this is a huge economic productivity issue in our country, So this is how we had the federal finance minister with the minister of social development and the health minister backing the change after the 2015 election when we made caregiving a real national priority.

Data Informed Caregiver Policies

- Canada's Canadian Institute for Health Information (CIHI) collects and reports standardized caregiver metrics using InterRAI Home Care Assessment Systems.



One of the other things we are lucky with is that we have a federal agency called the Canadian Institute for Health Information (CIHI). What is important about CIHI is that it collects and report on health. It doesn't make recommendations it just presents the data. And one of the great things we have on health information is that because we use the InterRAI Home Care Assessment System that is used in many countries around the world we are able to get from that relevant care giver metrics. It may not be as comprehensive as you like but some data is better than no data. And specifically, because these are related to the assessments of individuals who are receiving publicly funded home care for example, and we use the same system for people receiving publicly funded long term care or nursing home care, it allows us to understand and measure what we are actually seeing amongst family care givers in particular.

And so, I pulled out these three stats from one of their recent reports because it helps to understand what caregivers in general are experiencing versus someone who is providing care to someone with dementia. About 26 hours a week for example, and remember 1 in 3 Canadians is balancing work with unpaid care, so 26 hours is not insignificant, and for many people it is more than that amount of time. We also look at reported caregiver experience of distress. So you can see unpaid caregivers looking after someone with dementia you have 45% compared with caregivers of other seniors where it is 26%. Then you have this other statistic where caregivers supporting people with dementia are often reporting experiencing distress if the person receiving care displays verbal or physical aggression.



Dr Iva Holmerova

I appreciate this discussion. My opinion is that all (or nearly all) psychosocial interventions should be individualized (including reminiscence, music ...)



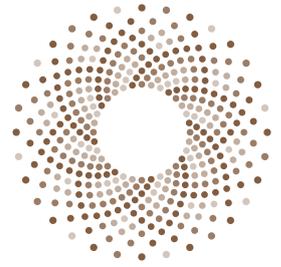
Professor Anthea Innes

Lenny, yes it is, but until we do so and find ways to do this more, we are not being fully inclusive in how we approach dementia care.



Sarah Lock

Yes Jaqueline, focusing on using the abilities of people with dementia, including what Anthea is saying, this has been a huge advance I see in the US but we need much more and as Lenny says scaling up is key



This is important because for example through my role with the Ontario government helping to develop its Seniors Strategy and looking at these issues, especially the issue of caregivers back to 2012, we actually track this data on an annual basis. And I remember being called a number of years ago because as we were looking at the data, we saw year over year the reported distress of caregivers increased by 10%. And this prompted a conversation with our ministry of health on how we can get ahead of this. So, this actually helped us toward the creation of a dementia strategy for Ontario.

DEMENTIA STRATEGY KEY INVESTMENTS										
	1	2	3	4	5	6	7	8	9	10
	Dementia Day & Evening Programs	Caregiver Respite	Care Partner Education and Training	Dementia Workforce Training and Education	Behavioural Supports at Home and in Community	Behavioural Supports in Long-Term Care Homes	Primary Care Collaboratives/ Memory Clinics	Patient Navigation	Continued investments in physician education in geriatric care	Dementia Campaign
INITIATIVE	Expand province-wide access to dementia specific programs.	Enhance flexible respite services for care partners of people with dementia.	Enhance education and training available to care partners.	More dementia-specific training hours and supports for front-line and primary care practitioners.	Expand Behavioural Supports Ontario program in home and community.	Expand Behavioural Supports Ontario program in long-term care homes.	Build on innovative models to increase access to specialised care.	Expand access to integrated and coordinated dementia care in the community.	Explore additional geriatric medicine and geriatric psychiatry residencies in partnership with the medical schools.	Expand Dementia awareness campaigns.
OUTCOME	More dementia day/evening programs, including transportation to and from programs for patients and care partners.	Improved access to respite supports, including in-home and overnight, to reduce care partner burnout.	In-person and online educational resources for care partners so people have the right skills to provide care for loved ones.	Giving front-line health care providers more tools and supports to better manage dementia.	Enhancing supports in home and community to help care partners manage complex behavioural health needs.	Expand Behavioural Supports across all Long-Term Care Homes.	Explore expansion of innovative models to improve patient diagnosis and appropriate management.	Additional care coordination support for newly-diagnosed people and their care partners.	Enhanced capacity for specialists to support the entire health workforce to respond to the needs of our aging population.	Targeted campaigns to key populations to educate the public and reduce stigma around dementia.

 **Professor Anthea Innes**

Felicity, lovely examples of creative approaches in your presentation, thank you.

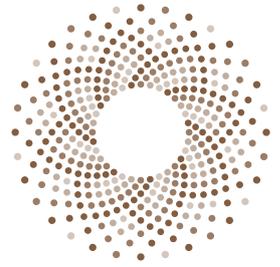
 **Emily Holzhausen**

My question to all the speakers is whether they think that Covid-19 has "super charged" progress/take up in the programmes that you are looking at? Across primary care support, tech, carer support and online music therapy. I think in many of our countries we've all seen an increase in the needs of people with dementia as well as their family carers. We have seen some really positive results, but equally with others the physical human intervention/ touch is also missed. When we come out of the pandemic, how what positive changes do you think we will see?

Ontario's previous government, after a few years of work, launched its own dementia strategy and really it looked at comprehensive pieces. Unfortunately, there was a change of government, these things happen, and the three-year funding commitments to accomplish all these tasks, were not necessarily the focus of the successive government. But we did get a few wins along the way.

I want to focus on items 2 and 3 that recognise the role of care partners and thinking about the role we can add on to those federal measures to provincially support caregiver respite and care partner education and training. And really thinking about for caregivers how we can give them support by making sure there is enough homecare available.

So one of the investments we did through our publicly funded homecare system is that we would now be able to allocate additional hours of homecare specifically for the needs of providing caregiver respite. So, this we identified a caregiver and there were issues of burnout I now as a clinician often able to request caregiver respite hours for my patients and their families. Which at least gives them additional hours not for care but for support. So it gives three hours for someone to have a break and go out for a walk for example, do the groceries, do whatever they want to do, just to sustain and support them better.



But we also recognise, and to Dr Sano's slides, we recognise the importance of care partner education and training. How do we support the resilience of caregivers as well?

www.dementiacarers.ca Programs Locations Resources About Us

Enhancing Care for Ontario Care Partners

Our clinical services and group programs help care partners manage the day-to-day care of the person living with dementia, reduce emotional stress and burden, and improve their ability to cope with the demands of caregiving.

Care Partner Programs

In-person and online clinical services and group programs.

- CARERS
- TEACH
- Mindfulness

Find a Program

Enhancing Care Program Partners and Locations

Programs offered in over 40 communities across Ontario.

Find a Partner Location

Resources for Care Partners

Award winning tip sheets, training and coaching videos, and interactive app.

Find a Resource

Now I really want to talk about one of the initiatives that has been funded as a result of Ontario's Dementia Strategy. It is a legacy initiative with permanent funding, so it is here to stay. My colleagues at Sini Health in downtown Toronto created this in partnership with Alzheimer's societies across Ontario and you can go and explore this at www.dementiacarers.ca. It is specifically funded to support people across Ontario but it has the opportunity to support people beyond that.

And it focuses on a variety of supports and services for caregivers. So as Dr Sano was just talking about thinking about how you leverage technology when so many people have that, and thinking about the barriers that you can overcome. These again are focussed on making sure people can have access either in person, pre-Covid, but all these programmes are accessible via the web. So, using zoom and video conferencing technology.

If you look under the care partner programmes in the first column you will see these acronyms of CARERS and TEACH. CARERS is basically a programme called Coaching, Advocacy, Respite, Education, Research and Simulation. This is an eight-week small group psychotherapeutic skills training programme using simulated patients. I have a lot of patient/caregivers who have gone through these programmes. When you do it in person, they have a dementia group, so you can bring your loved one and they have their own activity, while the caregivers have their own activity. And this is where they are working with simulated patients to re-enact situations is a difficult thing and to give them a problem-solving approach using simulation coaching skills so they feel more empowered in working in caring for their loved one living with dementia.



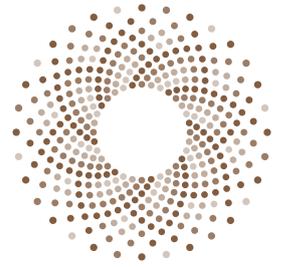
Jim Pearson

Participants might find this interesting. Published this week it sets out a bold transformational vision for the future of social care support in Scotland. It was commissioned by the Scottish Government in response to gaps which (not created by) but exposed during the Covid -19 pandemic.



Katie Brandt

It is often said that when a person is diagnosed with dementia, it is a dual diagnosis; one of dementia and the other of caregiver. If being a caregiver can impact your health, well-being and ability to fully engage in society, then care plans must be developed for both individuals. Plans that validate the carer role, offer education and encourage respite and support have the ability to



TEACH is a new programme that is a four-week skills development programme without the use of simulated patients. And again, this works on providing strategies for keeping a meaningful relationship with a person living with dementia. And the nice thing about these groups is that they are limited to 8 or 12 people through a zoom call. You actually make meaningful and personal connections with others. Many of these groups keep meeting on their own. It is all compliant with privacy requirements.

The final programme is a mindfulness programme as well. Again, really just helping a lot of caregivers to be supported in that way.

So, you can imagine these programmes were running pre-Covid which you could do in-person or online but because of the pandemic these are all being used online through the Alzheimer's societies and a staff of 25 across the province and being offered in-person when it can be in 40 locations.

Then there are other resources, as the final column there. One is a great app that I recommend to all my families, as per the Dementia Adviser app. A little skills-based thing that you can use for 30 or 40 seconds with problems such as my loved one is wandering how do I support them. Using it in a way to think about what is the problem and how can you problem solve. And many of these programmes have won significant awards.

What we always like to say with my team is that it is about investing in R&D, not necessarily research and development but rob and duplicate. So, if you want to learn more about these programme and how to scale them then my colleagues will be keen to help.



Professor Brian Lawlor

Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

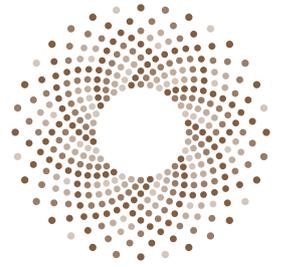
Thank you very much Samir. Just to let everyone know, we are running a little bit over but we will make sure we to leave plenty of time for discussion at the end. So, our next speaker is Felicity Baker she who is going to share her thoughts about how to support people with dementia with music therapy. Good evening Felicity!

improve quality of life for both individuals. How can our medical community help highlight this dual diagnosis?



Grace Whiting

Emily, one thing I worry about for all carers is that the modifications that have been made in the US system (such as relaxing telehealth regulations) will “go back to normal” once vaccinations become more widely available. Same with the expansion and energy behind a paid family and medical leave program on the national level. If anything, Covid-19 has revealed some of the major issues with our health and social care systems and it would be a waste not to take the moment for “lessons learned” to improve care delivery.



Professor Felicity Baker

Director of International Research Partnerships, Creative Arts and Music Therapy Research Unit, The University of Melbourne



Professor Mathew Varghese

The iSupport trial.



Professor Bill Reichman

At Baycrest in Toronto, the pandemic has greatly catalyzed our efforts to bring health care, recreational and social programming and caregiver supports out into the community by really leveraging technology.

Good evening everyone. Thank you so much for inviting me to share some of my work today. It is just a really great opportunity to highlight the value of music in the care of people with dementia. I hope I can present something in a coherent way! It is nearly 2am in the morning here in Melbourne! My brain doesn't normally focus so well at that time.



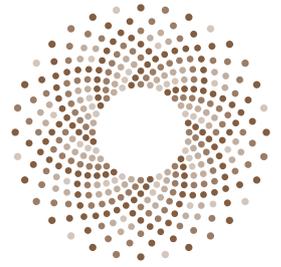
Professor Martin Knapp

We need to be careful not to generalize from research and experience in the high-income world to other regions, especially the Global South. It may be that task-shifting from established 'high-income country models' could be affordable, which is why the World Alzheimer Report 2016 explored such approaches. But a better starting point



So, I want to start by first just saying that music therapy is an allied health discipline that uses music to regulate arousal, reduce agitation and address other areas of behavioural and psychological symptoms of dementia. With the aim of helping carers and family carers to support the well being of people with dementia.

So, we have advanced training into how to harness the unique power of music to support health, wellbeing and the quality of life. With special expertise to attuning to



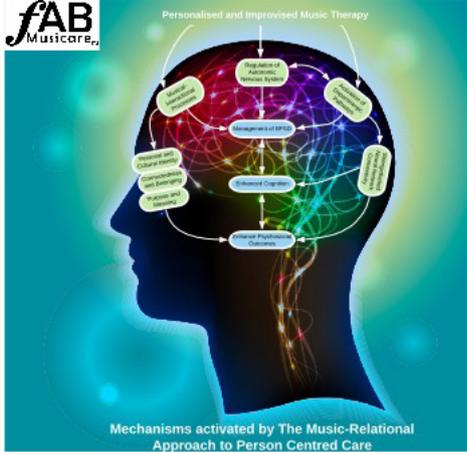
the emotional needs of these really vulnerable people. We really love to target in our work those who are typically unreachable either because they are non-verbal, palliative, experiencing depression or they don't share a common language with other people around them for those of a different cultural background.



How does music therapy work?

Activation of rich distributed bi-hemispheric neural network that can combat neurodegenerative decline.

Stimulation of interconnected brain structures commonly compromised in persons with neurodegenerative diseases.



Mechanisms activated by The Music-Relational Approach to Person Centred Care

So, we know from research that music stimulates the dopamine network in the brain. It regulates the autonomic nervous system and activates a rich distributed bi-hemispheric neural network that can combat neurodegenerative decline. We know from research that music stimulates interconnected brain structures that commonly compromised in persons with neurodegenerative disease.

And we combine that with a person-centred approach to help stimulate and engage vulnerable people.

It is not just the music itself that has these therapeutic benefits but the music interactional processes that happens when the music therapist attunes to the resident's emotional state through music that the change really happens. So, it is through this shared experience of musically stimulated autobiographical recall, that people with dementia have their identity acknowledged and reinforced. I always use the expression that the music helps you see the person behind the dementia.

is to support middle- and low-income countries to develop and explore (and evaluate) approaches that are culturally appropriate and feasible. Check the STRiDE study for information on what we are doing.



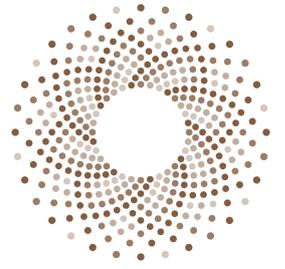
Professor Felicity Baker

Stefania, we are working on a training program that can be delivered by a mobile application to enable greater reach.



Emily Holzhausen

Grace, could not agree more. Some of the flexible working rights that Samir was talking about in Canada that we don't have here, apart from during Covid-19 are another good example. We don't want to lose the awareness of employers about employees trying to juggle work and care often for a parent, but sometimes for a



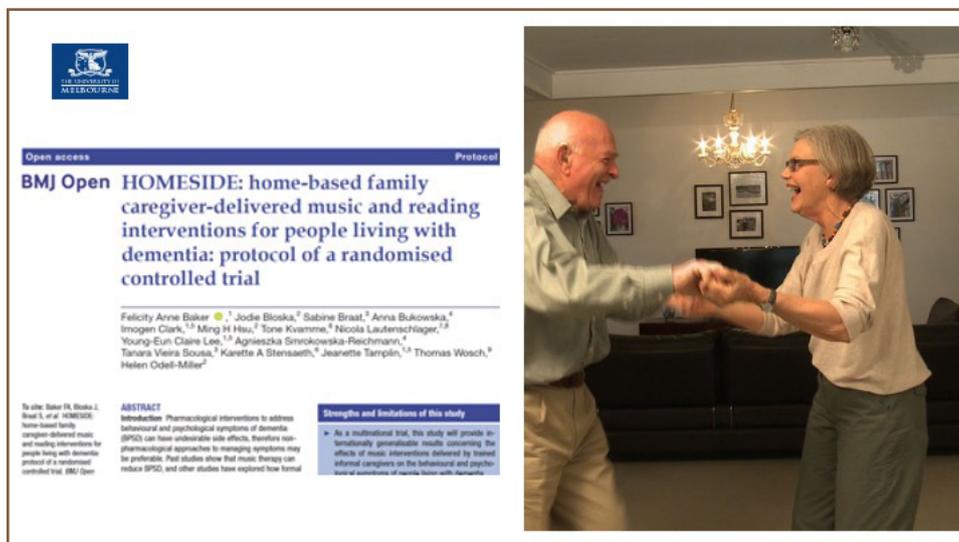
partner with early-onset dementia. In research with employers, we found that those who were already "carer friendly" were much more able to accommodate the flexibilities that family carers needed to care for relatives.

There has been a series of studies and meta-analyses that have been conducted to look at the specific impact of music therapy on people with dementia.

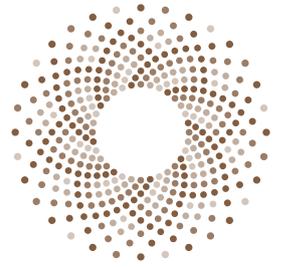
And I have just taken out, the soon to be shelved age-care funding instrument in Australia that had some items where they have used music therapy to address certain issues around care. But unfortunately, many of the studies that have been published so far have been pretty underpowered. Small sample sizes, lack of rigor in the design. That doesn't help us when we are trying to influence policy. I have been on an agenda to try and change that and implement some more highly powered studies.

 **Professor Kenneth Rockwood**

Agree with the observations about Covid-19 and dementia, technology uptake, related progress and stresses. Worth underscoring that Covid-19 threatens to reduce the worldwide decline in age-specific dementia incidence. In survivors, Covid-19 delirium seems particularly to unmask / gives rise to / accelerate cognitive decline. Especially so in older adults living with frailty at baseline.



So, I am going to introduce you to two I am involved in at the moment. The first one is called Homeside. It is a home-based family caregiver delivered music programme that is designed to help caregivers manage their loved one's symptoms and hopefully keep them home for as long as possible. It aims to enhance carers well being as well as the person with dementia and provide them with opportunities to meaningfully engage their loved one as they are caring for them rather than just attending to the day-to-day activities of showering and dressing.



We are hoping our research will show how the programme will reduce the economic impact by keeping people at home for longer but also less need for mental health care. And at the moment our trial is being rolled out in Australia, the UK, Germany, Norway and Poland.



What we do is provide family carers with three music or reading training sessions. We guide them how to use music and reading in strategic ways to regulate arousal. And how to maximise the possibility for reminiscence and meaning making during day-to-day activities but also as they are sitting down together at different points during the day. The beautiful thing about this, unlike pharmacological interventions, you can use this 24/7 and you can't really overdose on it.



Homeside
Partnership in dementia care

HOMESIDE

✉ homeside-australia@unimelb.edu.au

☎ **+61 (03) 90353057**

🌐 <https://www.homesidestudy.eu>

So, I just wanted to show you very briefly, as I know we are short of time, illustrate an example of where music is used to help this daughter of a person with dementia to regulate their arousal.



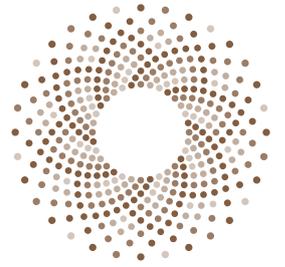
**Professor
Victor
Reginer**

I am an architect and find this discussion very interesting. I was wondering if anyone has experiences with outdoor spaces. We are finding these setting particularly helpful in healthcare environments. I love the Hogeweyk Dementia Village in Weesp. I have visited this place several times and I find it very useful in using outdoor spaces and activities of daily living for their 160+ residents living in 25+ small group clusters (houses).



**Professor
Vanina Dal
Bello-Haas**

Thank you for the excellent presentations, very informative. One of the many challenges relates to applicability whether it is context, or the need for individualized approaches e.g., interventions that





MIDDEL

Music therapy interventions to address depression and neuropsychiatric symptoms of people living with dementia

Prof Felicity Baker, The University of Melbourne
Prof Christian Gold, NORCE, Bergen, Norway (Principal Investigator)

Partner Universities:


NORCE
Australian Government
NIMRC National Institute for Dementia Research


UNO - UMCG
The University of Nottingham






Hopefully you can see the change there and we can discuss it during the discussion. We are actually recruiting for this study now and here is some information if you would like to know a little bit more about the study.

align with the stage of the disease course. Often we seem to focus on the later stages but there is a need to ‘live’ with having the diagnosis (both person and caregiver). Models of care typically address the here and now in a particular context (the box of research), the societal snapshot so to speak ... visionary models of care that will take us into the future are needed.




Group music therapy Choir Singing

Made Possible by Melbourne Campaign

The University of Melbourne
<https://youtu.be/CsGv3Q743pk>

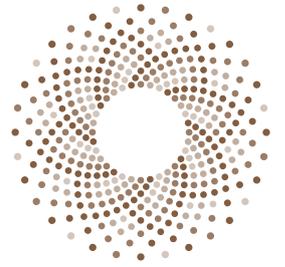
Recreational

University Research Changes Lives ‘ Campaign
 Universities Australia
<https://youtu.be/xUERivnYYY>

So, the second one I want to briefly touch on is our MIDDEL study, led by our Norwegian colleagues, that was rolled out in Australia in 2018, and we are wrapping up our data collection at the moment. But it is also being funded in Norway, the Netherlands, UK, Turkey and Germany and they haven’t yet, thanks to covid-19, been able to commence their data collection yet.

 **Professor Shekhar Saxena**
 Non-specialist care for dementia: see WHO’s mhGAP Intervention Guide.

 **Katie Brandt**
 Kenneth, thank you for bringing this up. We are hearing from our families that this is a significant concern, especially for those families who have loved ones living in skilled nursing facilities and memory care,





Settings and recruitment

Open access **Protocol**

BMJ Open Music Interventions for Dementia and Depression in ELderly care (MIDDEL): protocol and statistical analysis plan for a multinational cluster-randomised trial

Christian Góth,¹ Jasmin Eickholt,² Jörg Assmus,³ Brynuff Stiga,⁴ Jo Dugstad Waake,⁵ Felicity Anne Baker,⁶ Jeanette Tamplin,⁷ Imogen Clark,⁴ Young-Eun Claire Lee,⁸ Sine Lindahl-Jacobsen,⁹ Hanno Mette Ochaner Ridde,⁵ Gunter Kreutz,¹ Dorothea Muthesius,¹⁰ Thomas Wosch,² Enrico Ceccato,⁸ Alfredo Raglio,¹¹ Mirella Pluggen,¹² Annetiek Vink,^{11,12} Sytse Zuidema,¹¹ Heini Odell-Miller,¹³ Martin Ormel,¹⁴ Justine Schneider,¹⁵ Christine Kubiak,¹⁶ Renee Romeo,⁷ Monika Goretzinger¹

Abstract
In older adults, dementia and depression are associated with individual distress and high societal costs. Music interventions such as group music therapy (GMT) and recreational choir singing (PCS) have shown promising effects, but their comparative effectiveness across clinical subgroups is unknown. This trial aims to determine effectiveness of GMT, PCS and their combination for care home residents and to examine heterogeneity of treatment effects across subgroups.

Strengths and limitations of this study
As a multinational trial, this study will provide internationally generalisable results concerning the effects of music interventions in older adults with dementia and depression.
Based on previous small-scale studies, this trial will have adequate power to determine clinical effects as well as to explore variation in treatment effects in relation to patient characteristics.

	Residents	Staff Members
Assessed at Baseline, n	316	131
Age ^a	86.5 (7.2)	43.7 (11.8)
Female ^b	213 (68.3)	108 (82.4)
English as first language ^c	224 (75.9)	18 (15.3)
Other language (but having good knowledge of English)	45 (15.3)	-
Other language (and having poor or no knowledge of English)	26 (8.8)	-
Country of birth ^d		
Australia	183 (58.7)	-
UK	32 (10.3)	-
European countries	68 (21.8)	-
Other countries	29 (9.3)	-
Severity of Dementia ^e		
CDR 0.5 (very mild dementia)	17 (5.5)	-
CDR 1 (mild dementia)	46 (14.8)	-
CDR 2 (moderate dementia)	109 (35.2)	-
CDR 3 (severe dementia)	138 (44.5)	-
MMS ^f	8.0 (7.7)	-
MADR5 Scale ^g	18.4 (7.6)	-
NPI-Q - Severity ^h	10.9 (6.8)	-
NPI-Q Distress ⁱ	12.2 (11.0)	-
Staff category ^j		
Registered nurses	6 (4.5%)	-
Enrolled nurses	3 (2.3%)	-
Personal care attendants	114 (87.0%)	-
Liaison staff	8 (6.1%)	-
Work Experience (years) ^k	8 (4.9)	-

Notes.
^a n (%).

noting that their decline before and after Covid has stolen time that families were hoping to be able to share together.

 **Professor Louise Robinson**

Hear hear Sube.

 **Dr Ng Li-Ling**

Agree Sube!

 **Jacqueline Hoogendam**

Victor, you might be interested in the NL dementia care farms as well. Small scale living, 25-30 persons, in a farm like setting, with kitchen gardens, chicken, sheep, goat etc. With scientific background. Let's get into contact: jj.hoogendam@minvws.nl

 **Barbara Osborne**

Felicity, thank you for sharing how music can help to transform relationships between the caregiver and the

The study compares the effects of interactive small group music therapy delivered by a credentialed therapist with a recreational choir singing, what you could call a sing-along essentially. We are tracking the impact on depression, the neuro-psychiatric symptoms of dementia and looking at the health economic outcomes over a 12-month period, so it is longitudinal. The group music therapy aims to provide person-centred care with a real focus on biography and regulating arousal. It includes singing, dancing, movement, and reminiscence techniques. Whereas recreational group singing is conducted in non-therapeutic context and really just focuses on singing and is much more like a performance.

So, the study has randomised 316 participants in Australia. We had recruited another 85 and almost finished the baseline when covid-19 forced the lockdown of our care homes here in Melbourne. So, our final data set is based on 316.

That's all I have to say as I know we are pressed for time.

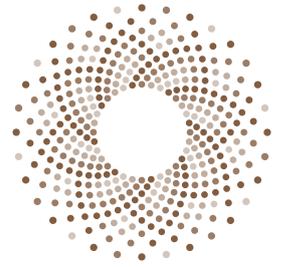


Professor Brian Lawlor

Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

Thanks so much and thanks for staying up so late. It was wonderful to hear your presentation. What I would like to do now is to provide some brief reflections to help frame the discussion, but I want to move into the discussion as soon as possible. There have been some very active conversations happening in the chat which is wonderful to see.

So, we are all here because we believe very strongly that we need to create new and equitable models for dementia care. In a sense, a new way of doing things that promotes hope and a better quality of life for people with dementia. There are a number of aspects to achieving this that have been touched on by our four speakers so far and I hope we can expand on in the discussion.



First of all, we heard about the need to take a joined up and integrated approach across health and social care with a focus on personalised care. Louise told us about creating an integrated care model and also how one size doesn't fit all. She also spoke about the fragmentation that exists in the system and how we might address it. Secondly, we need to have greater support for informal care givers. Sometimes the language we use, like 'caregiver burden', might seem to imply that being caregiver means having a problem. But caregivers are not a problem, they are a big part of the solution. And Samir talked about care partners and working in partnership: I really like that terminology and positive language and maybe that is one of the new ways to value and champion care givers, working in partnership with them, involving them and supporting them as they care. We must back this up through care giver policy and we heard a little about how Canada maybe moving in that direction.

Next, technology solutions that link care givers to the health and social care system is a very important aspect for a new model of care. And Mary pointed out how technology could provide information, facilitate communication between family caregivers and the healthcare team, for example through telehealth, tele-visits and caregiver training and education. And finally, Felicity emphasized the importance of harnessing the power of creativity, culture and the arts to promote brain health for people with dementia and caregivers. We saw a wonderful example of the power of music to change agitation into pure joy on one of her videos.

Ultimately to solve the problem of dementia care and find a new way of doing things we need to breakdown professional silos and work more effectively across discipline and systems. We must listen to people whose voice matters the most: that is people with dementia, their families and caregivers. Now, quickly moving to the discussion, Lenny said at the top of the hour that the meeting is about getting input from you, the international experts, on where we have come from, where we are, where we need to get to and how we get there. So, we are really looking forward to hearing your perspectives on that. This is the second half and we have about 30 minutes to hear from you. Please put questions to the speakers or share your own reflections. We will keep an eye on the video screens and we will also keep an eye on the chat functions.



Professor Morris Freedman

Head of Neurology and Medical Director of Cognition and Behaviour,
Baycrest Health Sciences

Perhaps I can start and say we are doing a very interesting new model at Baycrest that is having a major impact. What we have done is we have essentially created a virtual inpatient unit. Virtually we go into nursing homes, long term care and acute care. We see and assess patients with dementia and agitation and severe aggression. The kind of patients that need to be transferred to acute care hospitals, emergency units or specialised behavioural unit. By doing this virtually with a whole team approach we have actually managed to reduce the need for admission to acute care and to specialised unit by 80%. We are actually writing this up. What we have shown is that the model works. We can have patients who are very agitated, very aggressive, and we can actually treat them in their own environment. I want to share this that we have accomplish this with

individual. And, for the reference to how music helps you to see the person behind the dementia. As someone said previously on the chat, music creates a shared experience for the individual and their family members/care givers which enables a connection that may not otherwise be able to be achieved.



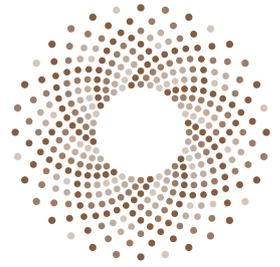
Lenny Shallcross

I recall seeing data that antipsychotic use is going up during Covid (I think this was in the UK) is there similar data from elsewhere?



Sarah Lock

Information and knowledge can transcend economic disadvantage in geographic and cultural division, and sharing information about improving the quality of life is very scalable.



all the problems with connectivity we do virtually rounds on a regular basis as often as every week going from facility to facility. So, this shows we can use technology to actually deal with patients who would otherwise have to be transferred to other health facilities.



Professor Brian Lawlor

Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

Thank you. That's a very positive report. Jacqueline perhaps you have a comment or questions.



Jacqueline Hoogendam

Dementia policy co-ordinator on Long-Term Care, Ministry of Health, Welfare and Sport, The Netherlands

Thank you I have a comment. Thank you to all the speakers for their very interesting presentations. I would like to say something about what we do in the Netherlands as usually care for people with dementia and their informal carers is focussed on their disabilities and compensating and helping people. Within our new national dementia strategy that starts this year and lasts until 2030 we also put a focus on the stimulus of using the abilities of someone with dementia. When you have a diagnosis, you talk about the implications of having dementia, the future, care but life and activities as well. So, we are stimulating programs like Dementalent where persons with dementia in early and moderate stage are doing volunteer work in a field they like. So they might be working in parks, or sports clubs or reading to pupils in primary schools or working in shops. More or less anything they like to do and are good at. So they have meaningful activities. Not just day care where they are kept busy but here they are doing something that feels worthwhile and meaningful and doing something for society. And research shows that when they come home the caregiver feels less burden and especially when these activities are combined with access to a meeting centre that improves the quality of life for the person with dementia and carer. Research shows admission to nursing home may be delayed by three months or longer on average. So I would like to say that dementia care in the Netherlands is not focussed on disability but focussed on abilities to improve quality of life.



Professor Brian Lawlor

Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

Thank you Jacqueline. I will just go to Mike Hodin now please.



Professor Louise Robinson

The potential of new drugs can also increase that shift away from the need for better person centred care once a diagnosis is made.



Professor Sube Banerjee

That's right Lenny, people are falling back on "simple" and poor ways of managing dementia.



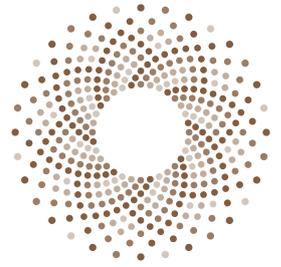
Sarah Lock

Yes agree, drug use increasing especially in the management of delirium so common in Covid partly in reaction to shortages of caregivers and the barring of visits by family caregivers



Barbara Osborne

We know that our live music sessions transforms the environment in residential care homes and provides benefit to both the



Mike Hodin
CEO, Global Coalition on Aging

Thank you. Pleasure to be here and really appreciate all the comments including in the chat functions that has really been fascinating. I would just make a couple of, if you will, higher-level comments. It would be to suggest we take this moment from a WDC point of view to really push it harder. All of the wonderful examples that we have seen, including the wonderful music therapy, can be scaled if we can deliver the type of strategic and political support that the WDC always had in mind.

There are three reasons this moment is unique, and Paul Hogan alluded to them at the beginning. One is out of Covid-19 the recognition of the role that caregivers have, it is just transformative. And now is a moment we have to take advantage of. The formal caregivers such as Home Instead but informal caregivers as well. The second is the first moment of the decade of healthy ageing. The third is we have cycled through seven years, who can believe it, but we are now back with the UK hosting the G7. It is the perfect moment to make a difference.

We are the perfect and right moment to make formal elder caregiving part of the health system. We have health care professionals, we have nurses, we have primary care physicians, geriatricians. Elder care giving is somewhere on the side. We have learnt out of Covid-19 that elder care giving is a profound and fundamental part of health care professional support. And we need to embed that into a health transformation. And secondly, and maybe our old friend David Cameron can help, it is more and more clear that elder care giving is an essential part of businesses role for the employee population. The irony of in many of our countries, corporations, even small businesses, thirty forty years ago providing childcare for the first time now what about elder care. As we all know it is lots of the same people who needed childcare thirty years ago that now need elder care today. Bring in CBI and Chamber of Commerce from the US, the corporate groups, to support the G7 to get elder care giving on the agenda.



Dr Mariella Guerra
Principal Investigator, 10/66 Dementia Research Group

I am from Peru South America a lower middle-income country. Great presentations they are paradigms of what we can do. However, I have heard not much about LMICs. What is going on in these countries. Since the World Dementia Council is an international charity it would be interesting to hear what is happening in these cities and countries.

residents and the care givers.



Professor Louise Robinson

Hear hear Helen.



Professor Anthea Innes

Well made points Helen.



Professor Vanina Dal Bello-Haas:

Thank you Helen, excellent points. I am a health care professional, a researcher ... but I also care for my mother who has dementia



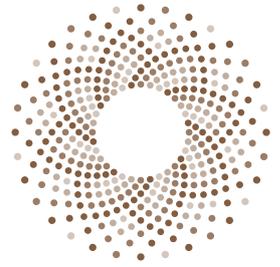
Jim Pearson

Totally Agree Helen - we need to shift the paradigm away from thinking about burden to investing in people.



Emily Holzhausen

Thank you Helen! Completely agree, as would so many of families we're in touch with and whom we support. So many people



Dr Stefania Illinca

Senior Atlantic Fellow for Equity in Brain Health and researcher, European Centre for Social Welfare Policy and Research

Thank you I wanted to make a very similar comment bringing it back to the issues of inequalities and to what extent the very interesting models that were discussed here today have relevance in a more global context. My expertise is in Europe but even in European countries much of the countries in the western Balkans or eastern part of Europe none of the interesting projects we have discussed exist or if they do, they reach no more than a minority of a population.

I wanted to make a similar comment about family caregivers. This is a highly heterogeneous group. Professor Robinson comment that no model is the perfect one is extremely relevant in this context as well. There are many models of support for care givers but they tend to be more specific for some group than others. So I think it is necessary to be a bit more specific about who it is we should try to help with priority and how to we address the need of these specific groups and how do we target them better.

don't have any care in the home or help right now. Am pleased you raised the importance of language.



Sarah Lock

Thank you Helen!



Grace Whiting

Agree w/ Helen re: the word "burden." It does not make clear that families are struggling with the impact of the disease on the family unit; rather it makes it sound like the person with dementia is the burden. The terminology needs to make clear that it's "us against the disease" and not "me versus the person with dementia." In our national study with AARP, Caregiving in the US, we actually have gotten rid of the "Burden of Care Index" and instead are using "Level of Care" Index. Instead of referring to "burden" we



Professor Brian Lawlor

Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

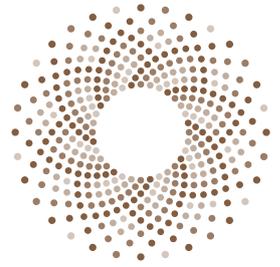
Thank you Stefania. I wonder Louise if this is something that you would like to comment on?



Professor Louise Robinson

Professor of primary care and ageing, Newcastle University

The same time we started this project, we also did one I am actually running that is a global health programme working in Malaysia, Ceryla and Tanzania. Similar work but not as far ahead because our data collection was interrupted by Covid-19. The interesting thing working in those three countries when they started to look at what service providers thought were within their countries they immediately said the solution had to lie with primary and community care teams ie non specialists. Because they had so many fewer specialists than we had in the UK. In Tanzania there were four neurologists in the whole country. There immediate response is that it is obvious that we look at non specialist ways of doing this. It is not so much the background of the individual but what care is needed what support is needed what are the issues for people with dementia and their families are in that country. And looking at how current resource can be used to deliver those in a feasible way. They very much saw, perhaps quicker in the UK where we have specialist model, a more generalist model is more more feasible.



Adelina Comas-Herrera

Assistant Professorial Research Fellow, Care Policy and Evaluation Centre (CPEC), London School of Economics

First, I had a slightly broader point which is about the advocacy that we need to achieve better care. A lot of the advocacy has focussed on drugs and achieving greater investment in finding cures and treatments. That is great. But that has meant there has been a lot of effort in advocacy in highlighting the cost of dementia and that is a cost that has to be got rid of. The problem is most countries are not spending nearly enough on care and we have seen this very clearly and dramatically with the Covid-19 pandemic. And I think it is very important that we think very carefully about what the best advocacy for care. And how we combine both. The case for greater investment in clinical treatments but also an advocacy that also works for care.

Here we need to change the emphasis and perhaps move much more toward showing what you can buy if you spend more on care and how you present a positive picture. And this links well with the STRIDE approach, Martin is the PI and is also on the call. STRIDE is a study that is happening in seven low- and middle-income countries where we are trying to understand what stakeholders think will be a good vision for improving care in the next 15 years in their countries, and then going back to estimate what are the resources that we need to achieve better care. We are trying to move the discussion away from linking dementia and costs without explaining that you are getting something better when you invest in care.



Professor Brian Lawlor

Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

Great. I am going to move to Sube, then to Radha and then Helen.



Professor Sube Banerjee

Professor of Dementia and Associate Dean, Brighton and Sussex Medical School

Great talks and a great meeting. Two quick points. The first one is about the fact we need to be very careful about the priority we have gained for dementia in the last 10 years. We need to be very careful because it can slip away at this point. It is very much the case that people with dementia have taken the brunt of the Covid-19 pandemic with between a third- and two-thirds of individuals who are dying doing so in care homes with the majority of those being people with dementia. Essentially people with dementia have been used as a human shield to protect other areas of society and the health system.

But if you look at the quality of care that is now being provided for people with dementia and you look at the priority that people are giving both in political and policy circles you can see we have essential gone back 10 years in 10 months in terms of the priority. If you look in the United Kingdom you see the rate of antipsychotics is increasing, people

are now measuring level of intensity or complexity of the caregiving situation.

[More here.](#)



Dr Ng Li-Ling

Well said!



Dan Wieberg

Helen, while some refer to caregiving a burden, my siblings and I would all agree that when we cared for my dad, who had Alzheimer's, it was the most rewarding experience of our lives.



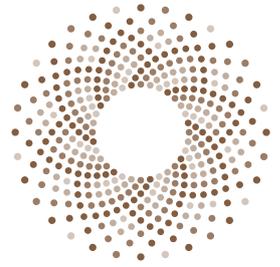
Professor Victor Reginer

I found the music presentation particularly helpful. More on techniques might be more evocative for all of us.



Sarah Lock

Huali, great point, I will see if AARP has something on this already or to see if we need to do it



are not getting good quality face-to-face assessments and diagnosis. There is a whole manner of things.

We are at a very sensitive time. We need to work very hard to make sure the brilliant achievements of the last ten years are not lost. Because what is happening is the system is reverting to hard-wired beliefs around what its priorities are, and these include infectious diseases and cancer and all those things that do not include dementia. We were training the system, but the system is not hard-wired to make dementia a priority. We need to be really careful and quick about recovering our position and reasserting the priority of dealing with dementia which is actually the 21st century priority.

So that is the policy side of things. The second side of things is, as has been said earlier, in terms of the solutions for dementia we really must not over emphasize the importance of medication. We need to reemphasise the power of care for people with dementia. The problem is there is not nothing we can do for people with dementia. The problem is there is so much we could do to improve the quality of life for people with dementia that we are not doing. That is the missed opportunity that we are in at the moment and that is what we need to focus on really hard.



Professor Louise Robinson

We need to redress the balance of money spent on drug research compared to care research... still a big issue.



Professor Mathew Varghese

Most caregivers in India feel it is a pleasure and sometimes a duty to care for their loved one.



Sarah Lock

So agree Louise



Professor Brian Lawlor

This is a step forward!



Lenny Shallcross

Mary's stat on tech (71% interested to 7% use was stark) but maybe particularly in LMICs tech will be more rapidly sued



Professor Brian Lawlor

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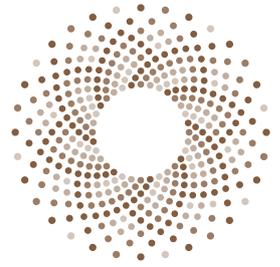
Thanks Sube and that is why this workshop is timely for all those reasons.



Radha Murthy

Co-founder, Nightingales Home Health Services and Nightingales Medical Trust

It was a great learning for me, especially because knowledge of dementia is lacking in India in spite of it being a emerging problem. Though we have tried various models of care, online dementia support services, the priority here is to bring down the cost of care. At present, use of technology is the only answer for the same. I noticed that you were talking that caregiving is mostly by adult carers who have difficulty in using technology. Here in India, we have mostly young formal carers or family carers. The family carers are not compensated. In India there is lack of awareness, technology, societal support systems. Keeping this in mind , I feel that we have a long way to go . Today's discussion helped me to understand the diversity of the challenges in dementia care.



Professor Brian Lawlor

Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

Thank you. I am going to go to Helen.



Helen Rochford-Brennan

Global Dementia Ambassador and Chairperson, European Working Group of People with Dementia

Thank you very much for having me here as the voice of the person with the illness and I am so delighted with all of your presentations. After nine years of living with Alzheimer's I am sad in some ways that we are still talking about pathways of care. I am also sad that I think we have gone back nine years with how care is going to be with Covid-19. We have taken the brunt without any question. We are dying in care homes. We are left at home without care, without family support, without, which is the most important thing to us, community support without interaction with our communities. I just wanted to say that it is really important for me to say that pathways of care and models of care there is so much we can talk about and so much you have all talked about which is great. Louise touched on that there were still so many inequalities. That is the way many of us with dementia feel that we have all of this research going on, but we just want to tie it together so that we are not reinventing wheels and we have a pathway of care.

And can I just say that when I saw the agenda the thing that really touched me and Professor Lawlor and myself may have touched on this at some stage. The word burden. It actually makes me and my colleagues extremely sad when that word is used. I just want us to consider your loved one: would you consider thinking that you can assist them, which is the greatest joy that you give a member of your family, to try and give them a quality of life. It is such a beautiful thing. And it supports us in every way possible when our families do it. So, to consider the word burden because you are assisting us and because there is a burden on you assisting us. The word has one place for me, and it is in the trash. I think it is about time I speak, I am sure everyone over the world, that that word does not belong in taking care of a person with dementia. You do not hear about anyone talking about the burden of caring for someone with Parkinson's or Multiple Sclerosis or many other illnesses. You just hear about it for people with dementia.

I just want to talk about the joys of art and music, we had them when we got this illness, and we want to continue have them in our lives. So, a care pathway that has arts and music and not just our medical needs is critical. And on that note, I want to finish, and I want to thank you all for what you are doing. But I just hope that we are not forgotten about, as Sube so rightly said we have gone back. We want the research to continue. Health research and care.

We want to stay in our own communities and our own homes for as long as we can. In every country of the world. I am so delighted to hear about Canada. We need funding. We need our governments step up to the plate. I have yet to hear over all of Covid-19 that the



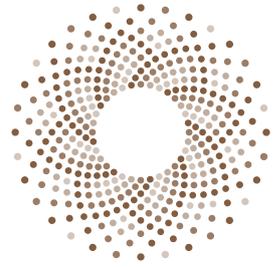
Stecy Yghemonos

On the topic of burden - caregiving can indeed be a great source of satisfaction but only when support is available and caregiving does not take place at the expense of the carer's social and professional life. This reminds me of the testimonial of a carer I met a couple of years ago and said: Caregiving is not the source of my stress and exhaustion, the constant battle for services is!



Jim Pearson

Also agree Helen that sometimes that the problem is not knowing how to support people with dementia, their families and carers, from diagnosis throughout their life is about implementation. In Scotland we have progressive dementia policy and less progressive



person with dementia has not been diagnosed whatever type they have. So, I wish you all well and thank you for having me with you today it is a great pleasure for me.



Professor Brian Lawlor

Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

Thank you Helen. Martin we might have time for some words from you, then Mathew and then Huali.



Professor Martin Knapp

Professor of Health and Social Care Policy, London School of Economics

I will be very quick. Firstly, great meeting. Two things to say in terms of priorities. One is we really need to work on awareness and understanding and stigma, certainly when we move outside the high-income part of the world. Secondly, I want to appreciate what Helen and Adelina said. I may be the only economist on the call. There is no economic theory that I am going to talk about. Only good costs and bad costs. That is what Adelina is talking about. We tend to think of people as a burden. We tend to think spending on dementia is bad. We need to turn it round and see the resources we have in the area are possibilities for great opportunities. So, let's think about the good expenditure than the bad costs.



Professor Mathew Varghese

Professor of Psychiatry, National Institute of Mental Health & Neuro Sciences, India

Some quick points. I said some remarks in the chat. I support the experience in India, we need to make the online dementia courses very brief and available. Putting them on mobile or tablets and allowing families to choose from many options is most useful. Detailed assessments, such as the like you have to do for an RCT, is always problematic. Most RCTs become very challenging in their outcomes.



Professor Brian Lawlor

Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

Huali do you want to have the last word?

implementation and reach into people lives.



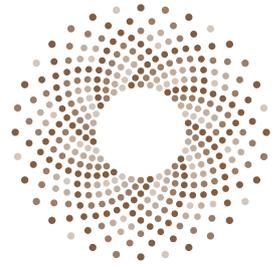
Professor Sebastian Crutch

Would be good if in the report and our future discussions the general issue of CONTINUITY could be highlighted. Time and again 'what' support is provided is emphasised over 'who' is providing that support. And yet huge financial resource and personal effort and energy goes in to re-making relationships and re-telling stories and situations in a new challenge – referral – discharge cycle. Louise's primary care work is key here, but many other services could be much better in maintaining individual relationships over longer periods.



Sarah Lock

Terrific event -- thank you Lenny and Josh.



Professor Huali Wang

Professor and Chair for Clinical Research, Director of the Dementia Care and Research Center, Peking University

Thank you very much. It is my great pleasure to join. The lectures were quite excellent. Currently we do not have very much information to support carers to enable them to make decisions about what technology to use to support a person with dementia. Particularly as technology has been advanced.

In the future it is whether we can do some research to build such decision-making processes.



Professor Brian Lawlor

Professor of old age psychiatry at Trinity College Dublin, and deputy executive director of the Global Brain Health Institute

Thank you so much. And now I will just hand back to my go chair Paul to close us out.



Paul Hogan

Chairman of Home Instead® and member of the World Dementia Council

Thank you. It has been a great session. There is so much to react to in such a short time. We talked about the great research we have today but we need to build awareness for it. Particularly research that uncovers the value of care. That is going to drive change.

A diagnosis of Alzheimer’s or dementia can be paralysing for a family. We see this literally thousands of times a day. The change needed is one that leans toward family and home. Home is the most scalable venue for care. It is the most desirable, more cost effective and, as Covid-19 has proven, it is the safest place to age. All the stars are aligning on this one.

We must support family caregivers and care partners. Longer stays at home mean shorter stays in more expensive forms of care by less people. I liked particularly liked what Professor Baker showed us that music can do. It brings the dignity.

These are all human beings each with unique stories and powerful emotions. Mahatma Gandhi said, The true measure of any society can be found in how it treats its most vulnerable members. So, I am happy to have been part of this and I applaud you for all you are doing. Thank you!



Helen Rochford-Brennan

Can we tweet?



Professor Louise Robinson

Honour to be invited.



Professor Mathew Varghese

Agree with Sube and Helen about how Covid has caused a set back. Elders are isolated as others feel they may transmit Covid to them!



Adelina Comas-Herrera

Thank you, great reflections and event.



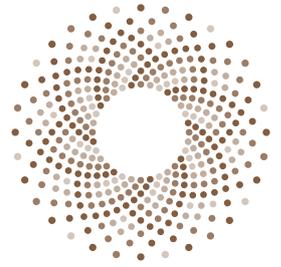
Katie Brandt

Thank you to everyone for this inspiring workshop! I hope you all will be safe and well!



Jacqueline Hoogendam

Great! Thank you Lenny, Josh and everybody else.



Lenny Shallcross

Executive director, World Dementia Council

Thank you Paul and Brian. Thank you to everyone who has participated. As I said we will send round a transcript including the transcript of the chat where people have put links. Then after that send round a number of essays from individuals reflecting on the discussion. And then finally send round a draft chapter for a report which we will invite comments on that we will launch later this year at, and I say this with some trepidation, at an in-person event when we will finally all get to meet.

So in the meantime it has been great having this opportunity to meet and I have a great rest of your day.



Emily Holzhausen

Thanks so much. It has been inspiring.



Dr Ng Li-Ling

Great session! Thank you.



Barbara Osborne

Thank you very much for inviting me.



Jim Pearson

Thank you.



Professor Anthea Innes

Thank you, great session.

The World Dementia Council (WDC) is an international charity. It consists of senior experts and leaders drawn from research, academia, industry, governments and NGOs in both high-income and low- and middle-income countries, including two leaders with a personal dementia diagnosis. The WDC has an executive team based in London, UK.

worlddementiacouncil.org

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